PSYCHOLOGICAL DISTRESS IN CARERS OF HEAD INJURED INDIVIDUALS: WAYS OF COPING, LOCUS OF CONTROL, SOCIAL SUPPORT AND THE PROVISION OF WRITTEN INFORMATION.

by

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Declaration

"This thesis has been composed by myself and the work contained herein is my own."

Katharine Clare Morris

ABSTRACT

Since the early 1970's researchers have expressed concern about the emotional well being of family members after traumatic brain injury (TBI) and it is now widely acknowledged that TBI has long term effects on the patient and relatives alike. Researchers have found a substantial number of relatives caring for head injured patients to show significant levels of anxiety and depression and have emphasised the need for information for relatives on the prognosis of head injury. There are, however, very few studies that have investigated the usefulness of giving literature to relatives. Using a longitudinal, mixed variable, within and between subject design, the present study investigated the effect of an information booklet on levels of distress in a group of 35[1] carers of individuals with TBI. The role of individual coping strategies, locus of control and social support were also considered. The participants were either caring for someone two to nine months post injury (early) or one or more years post injury (late). This allowed for the hypothesis that those carers in the early group would show a greater reduction in psychological distress than those in the late group. These results are discussed and the proposal made that an information booklet such as the one used in the present study should become an integral part of the discharge procedure for relatives of individuals who have sustained a head injury.

[1] It should be noted that this abstract was submitted prior to the completion of the study and as such it is inaccurate. The actual number of participants included in this study was 33.

CHAPTER 1 - INTRODUCTION

1. INTRODUCTION

1.0 GENERAL INTRODUCTION

Head Injury affects large numbers of people every year and its consequences are far reaching. It not only affects the individual who sustains the injury but those around him/her are also affected.

Since the early 1970's researchers have expressed concern about the emotional well being of family members after head injury and it is now widely acknowledged that head injury has long term effects on the patient and relatives alike.

Many studies have looked at the needs of carers of head injured individuals and have found a particular desire for information regarding the patients physical, cognitive, medical and behavioural status. The purpose of this study is to measure levels of distress in carers of individuals with traumatic brain injury; to look at the role of individual coping strategies, social support and locus of control when considering distress and to investigate, a) the overall impact of providing information on carers' distress, and b) whether type of coping strategy adopted, social support, locus of control, time since injury and/or severity of injury influence the impact of the information given.

In the introduction the opportunity will be taken to explore some general issues surrounding head injury and its sequelae before going on to consider the consequences of head injury on the family. The relationship between these consequences and coping strategies, social support and locus of control will be examined and the influence of providing information reviewed.

1.1.0 Head Injury – What Is It?

Traumatic Brain Injury has been defined as, "...an insult to the brain, not of a degenerative or congenital nature, but caused by an external force, that may produce a diminished or altered state of consciousness" (Rose and Johnson, 1996).

Approximately one million people attend hospital in the United Kingdom each year as a result of having a head injury. Of these, one hundred and fifty thousand will

have a minor brain injury, ten thousand will have a moderate brain injury and up to eleven thousand will suffer severe brain injuries (Greenwood, 1991). Approximately half of these are a result of road traffic accidents. Other causes include domestic and industrial accidents, sports and recreational injuries and assaults (Headway, 1991). High-risk groups have been identified as individuals between the ages of fifteen and twenty-nine (other sources suggest fifteen to twenty four (Lezak, 1995)). Over the age of seventy-five (Oddy, Coughlan, Tyerman and Jenkins, 1985) and between zero and five years old (Lezak, 1995) are also peak times. Individuals in lower socio-economic groups, alcohol or drug abusers, sufferers of psychiatric illness and sufferers of epilepsy are also high-risk (Headway, 1991, Lezak, 1995). The National Head Injuries Association, Headway, suggests that in the U.K. one in every 300 families is affected by head injury (Headway, 1991). There has been an enormous growth of interest in this area, especially an increased awareness of the needs of the person who has survived the head injury and also the needs of their family (Ponsford, Sloan and Snow, 1996).

1.1.1 What Happens In Head Injury?

A head injury is not just one but a series of injuries. The initial injury or initial damage occurs as a direct result of the accident and occurs immediately, at the time of injury. The blow at the point of impact is called the coup. Contre coup results in contusion (bruising) in an area opposite the blow. Coup and contre coup lesions account for specific and localised behaviour changes that accompany closed head injury. As a result of the rapid deceleration that occurs during an accident, the brain is "slammed" around within the skull often resulting in bruising. This rapid deceleration can also occur following a blow to the head or even with whiplash (Lezak, 1995). The movement of the brain described above may also result in strain being put on the nerve fibres and blood vessels within the brain. As a result shearing of these nerve fibres and vessels occurs. This is generally concentrated in the frontal and temporal lobes but diffuse axonal damage can occur. The secondary injury or the secondary damage may occur one or two hours later and results from complications that occur intra and extra cranially. This damage may be as destructive as the accident's immediate effects. Secondary damage is essentially caused by a

reduction in the flow of oxygenated blood to the brain. Rose and Johnson (1996) describe the types of complications that may occur (p.23).

Table 1: Complications That May Occur Following Initial Head Injury

Intracranial
Changes in cerebral blood flow (areas of high and low flow)
Reduction in brain oxygen supply
Swelling of brain substance (cerebral oedema)
Raised intracranial pressure
Loss of autoregulation (impaired control of cerebral perfusion)
Extracranial
Hypoxaemia (low blood oxygen levels)
Hypercapnoea (high blood carbon dioxide)
Hypotension and Hypertension (low and high blood pressure)
Changes in heart rate (increases and decreases)
Pulmonary oedema (fluid in the air spaces of the lungs)

Advances in medical technology, such as better emergency training (Frosch, Gruber, Jones, Myers, Noel,Westerlund, Zavinsin, 1997) and improved acute management, particularly in preventing damage from secondary injury (see later)(Smith, 1996, in Rose and Johnson, 1996), have resulted in an improved survival rate following serious head injury.

Types of head injury – A closed (diffuse) injury, where the skull remains intact and the brain is not exposed, is the most common. When the skull is penetrated the injury is described as an open (penetrating) injury. There may be significant tissue damage following a penetrating injury and this tends to be concentrated in the path of the penetrating object. Penetrating injuries account for less than 10% of all documented head trauma in the civilian population (Lezak, 1995). A third type of

injury is known as a crushing injury where the head is caught between two surfaces. These are rarely seen.

1.1.2 Severity

The depth of unconsciousness is often measured on the Glasgow Coma Scale (GCS) (Teasdale and Jennett, 1974). This widely accepted classification is useful for predicting outcome and treatment needs. The scale rates eye opening, motor response and verbal response yielding a score that ranges from 3 to 15 (see Rose and Johnson, 1996 for more detailed discussion). In terms of severity the accepted definitions are as follows:

Table 2: Glasgow Coma Scale Scores and Corresponding Severity of Injury

GCS Score	Severity
3 – 5	Very severe
6 – 8	Severe
9 – 12	Moderate
13 – 15	Mild

However, when the scale is applied within the first hours or the first day post injury, as intended, the GCS fails to classify exceptional cases. Those individuals who present with little or no loss of consciousness but who suffer significant deterioration two or more days later, are often misclassified.

Often the patient is conscious, with a GCS score of 14 or 15, but is still confused; it is therefore necessary to have a measure of orientation and amnesia. Some investigators rely on posttraumatic amnesia (PTA) as a measure of severity. It correlates well with GCS ratings. PTA is measured by orientation in person, place and time and extent to which the patient is amnesic for recent events.

Table 3: Length of Posttraumatic Amnesia and Corresponding Severity of Injury

Length of PTA	Severity
< 10 minutes	Very Mild
10 – 60 minutes	Mild
1 – 24 hours	Moderate
1 – 7 days	Severe
> 7 days	Very Severe

Some individuals may be discharged home while still in PTA making it difficult for investigators looking at medical records later, to estimate duration of PTA. Difficulties in defining and therefore measuring duration of PTA have also make its usefulness as a measure of severity questionable (Lezak, 1995).

A belief that the brain was a hard wired system led to the assumption that there was no need for rehabilitation and researchers paid little attention to outcome following head injury. However, this view has now changed and the literature over the past ten to fifteen years has heightened awareness of the diverse outcomes following head injury.

1.1.3 Outcome Following Head Injury

Rose and Johnson (1996) suggest that outcome should be regarded as, "a measure of the extent to which, following traumatic brain injury, a patient is able to resume his/her normal lifestyle." The literature in this area suggests that outcome following brain damage is different to other disability types and Florian, Katz and Lahav (1989) use the example of spinal chord injury (SCI) to illustrate the different impact and outcome. Both brain injury and SCI cause drastic changes in the life of the injured person, however, in SCI the implications are mostly physical, whereas in brain damage, in addition to any physical problems there may also be cognitive, emotional and behavioural deficits. Lezak (1996) suggests that the disability of

functioning following brain damage is considerably greater than the cumulative effects of the parts. Thomsen (1984) reports that in her study of outcome some 10 to 15 years following head injury, "..no one escaped permanent sequelae."

The majority of those who survive a severe brain injury (and even a moderate or mild brain injury) will survive with impairments which interfere with daily living (Jacobs, 1988). These impairments include:

- Physical
- Cognitive
- Emotional and behavioural
- Social

1.1.3 (a) Physical Problems

The most common physical consequences of head injury are epilepsy, motor deficits and impairment of sensory function. Brooks, Campsie, Symington, Beattie and McKinlay (1986), in a study concerned with outcome following severe head injury, asked relatives to report any changes that had emerged in the patient following their injury. Adopting a semi-structured interview format, the investigators asked questions about the patients' physical and mental state, behaviour and self – care skills. The mean number of physical difficulties reported by the relatives at one year and five years post injury were 2.4 and 2.6 respectively. Brooks et al. report that in their sample (n = 55) gross physical disturbance was unusual with 88% of patients fully mobile at one year and 93% at five years.

However, although the person may be physically well enough to return home there are still continuing cognitive, emotional and behavioural difficulties to be faced (Gronwall, 1997).

1.1.3 (b) Cognitive Problems

There is a well established literature on cognitive deficits following head injury which include problems with memory, attention and concentration, speed of information processing, visuo-spatial and perceptual abilities, language and executive function.

This study will focus particularly on the emotional and behavioural aspects of outcome following head injury, however, it is vital to have an understanding of the cognitive sequelae that impact directly on the emotional and behavioural outcomes.

Attention and concentration problems are common following head injury and are closely linked to fatigue. It is common for the head injured person to have a difficulty filtering out irrelevant stimuli and therefore carrying on a conversation, for example, in a noisy room, would prove extremely difficult and very tiring because of the level of concentration required. Relatives in one study rated tiredness amongst the top ten problems following head injury (Brooks et al., 1986).

Memory problems are also very common and usually consist of difficulties with acquisition and retrieval of information. Thomsen (1984) found that at least 80% of the participants in her study had memory deficits two and a half years post injury. Brooks et al. (1986) found that memory problems were the third most frequently reported problem by relatives of head injured individuals at one and five years post injury. The problems reported included the head-injured individual forgetting what he was doing in the middle of an action sequence, or losing track of what he was saying. Relatives reported that these problems seemed to get worse over the five-year period that they were involved in this study. However, they did not feel that the memory problems made a significant impact on their injured relative's life.

Masson, Maurette, Salmi, Dartigues, Vecsey, Destaillats and Erny (1996), in a five year follow up of head injured individuals with mild, moderate and severe injuries, found that the frequency of fatigue, memory problems and mental impairments increased with severity.

Due to the diffuse axonal damage which can occur as a result of the injury the previously efficient transmission system no longer runs as smoothly, the head injured individual's speed of processing information is therefore likely to be slowed.

Language problems may also occur. Word-finding difficulties and misnaming objects are common problems. Many of the participants in Jacobs' (1988) study reported problems with clarity, fluency, diction and pacing their speech. Speech abnormalities may result from physical damage; damage to particular areas of the brain may lead to comprehension difficulties and/or word finding difficulties.

Problems of attention, reasoning and memory may also lead to conversational problems and frontal damage may lead to impaired non-verbal communication.

The individual's ability to plan and recognise and choose from a number of alternatives may also be impaired. Deficits may also exist in the individual's capacity for self-determination, self-direction, self-control and regulation, all of which depend on an intact awareness of one's self and surroundings. Lezak (1995) said that this was not about the ability itself but rather "whether or how the ability will be expressed". Often what is required is there but it doesn't occur to the person to use these skills.

It is obvious that the many cognitive deficits following head injury continue for many years after the individual appears physically well. Although it is true that these cognitive sequelae do improve following head injury, this is an extremely long process and some skills may never return to their pre injury levels.

1.1.3 (c) Behavioural and Emotional Problems

Behavioural problems may arise,

a) as a direct result of the neurological damage, particularly damage to the frontal lobes that work to regulate emotions and effect motivation, self-control and self-awareness. If these controls are not working as well behaviour problems may seem an exaggeration of premorbid personality.
b) as a result of the stress of adjustment to a head injury and its many changes and losses. This may lead to frustration and this, combined with the direct effects of the damage can make problems worse.
c) as a result of inappropriate and/or unsupportive social and physical environments.

Behavioural and emotional problems reported in the literature include: impulsivity (as a result of control problems), agitation, anger and irritability, emotional lability, self-centredness (and often lack of awareness of social signals), apathy, depression and anxiety and inflexibility (Linn, Allen and Willer, 1994; Oddy et al., 1985; McKinlay, Brooks, Bond, Martinage and Marshall, 1981; Jacobs, 1988; Thomsen, 1984 and Lezak, 1988). Much of this work has been carried out through contact with

the relatives of the head-injured person and has highlighted the importance of these "unseen" changes.

McKinlay et al. (1981) interviewed the close relatives of fifty-five head-injured individuals and identified seven categories of problems. These categories were: physical, language, emotional, dependence, subjective, memory and disturbed behaviour. Of the ten problems most frequently reported at 3, 6 and 12 months post injury the majority fell into the emotional and disturbed behaviour categories. For example, 63%, 69% and 71% of relatives at the three time points reported that their head-injured relative was irritable. These findings are consistent with other work carried out in this field (Jacobs, 1988; Brook and McKinlay, 1983; Oddy et al. 1985; Lezak, 1988 and Weddell, Oddy and Jenkins, 1980). Brooks et al. (1986), in a follow up of participants from McKinlay et al.'s (1981) study found that the percentage of relatives reporting personality changes in their head-injured relative had increased from 60% at one year to 74% at five years. They also found that reports of irritability remained high, at 64%, and that reports of threats of violence had dramatically increased from 15% at one year post injury to 54% five years after the injury. Thomsen (1984) argues that even ten to fifteen years after the initial injury emotional and behavioural problems of this type persist.

It was noted above that the majority of these studies rely on relatives' views and reports for their information. However, Oddy et al. (1983) interviewed both relatives and patients and found that in terms of personality change patients and relatives reported similar symptoms. Masson et al. (1996) also interviewed head-injured individuals directly. Individuals with mild, moderate and severe injuries reported anxiety, depression, irritability and anger (see also Linn, Allen and Willer, 1994).

1.1.3 (d) Social

a) Occupation - The return to work following a head injury is a major challenge particularly given that those most at risk from head injury are within the age range where they are involved in training and/or at the outset of their careers. Oddy, Coughlan, Tyerman and Jenkins (1985) report a two and seven year follow up of individuals with a severe head injury. Their findings are presented below:

Table 4: Occupation Following Severe Head Injury (n = 43)

Work Status	2 years post injury	7 years post injury
Return to former job	5 (11%)	9 (21%)
Full time at a lower level	11 (25%)	6 (14%)
Housewives	3 (7%)	5 (11%)
In and Out of jobs/ physiotherapy	5 (11%)	3 (7%)
Day Centre	9 (21%)	8 (19%)
At Home	11 (25%)	12 (28%)

Thomsen's (1984) findings appear to support those described above. At 2.5 years post injury two (5%) patients in her sample were in full time employment and four (10%) in part time employment. Three (7.5%) were in paid sheltered work. In her sample, 93% had a disablement pension 10 – 15 years post injury.

Jacobs (1988), in a larger study (n = 310) of individuals with moderate and severe head injuries, found that pre-injury, wages were the main source of income for 78% of the participants compared with 27% post-injury.

Studies suggest that unemployment is related to emotional and behavioural problems, reduced stamina and poor memory, concentration and attention (Tyerman, 1996; Jocobs, 1988). Tyerman (1996) goes on to suggest that when these problems persist the head injured person may easily lose their confidence and become anxious about their abilities. In a study by Willer, Allen, Liss and Zicht (1991) head injured males reported that the loss of their role as a provider was one of the most challenging problems following head injury.

b) Leisure and Social Activities – There is a definite consensus in the literature regarding the dearth of leisure and social activities amongst individuals with head injury (Weddell, Oddy and Jenkins, 1980; Oddy and Humphrey, 1980; Thomsen, 1984; Oddy, Coughlan, Tyerman and Jenkins, 1985; Tyerman, 1996). Oddy and Humphrey (1980) report that 50% of their sample were still engaged in fewer leisure activities two years post injury. Oddy, Coughlan, Tyerman and Jenkins (1985) found that this situation remained unchanged at seven years post injury and Thomsen

(1984), in a separate study, reports a similar picture ten to fifteen years post injury. Jacobs' (1988) participants reported that as carers they were the major source of support and socialisation for the head injured individual.

This lack of occupation and leisure activities inevitably leads to the head injured person becoming socially isolated as friends (and employers) gradually realise that the person is no longer as before (Oddy, Coughlan, Tyerman and Jenkins, 1985, Tyerman, 1996).

1.2.0 Families

Head injury has a major impact on the family in that families often fulfil a vital caring role for the injured person following the injury. Pearlin, Mullan, Semple and Skaff (1990) suggest that "caregiving" refers to, "activities and experiences included in providing help and assistance to relatives or friends who are unable to provide for themselves." They go on to suggest that there is both an affective and a behavioural component to giving care. Researchers in this area have consistently found adverse effects on caregivers' psychological health (Panting and Merry, 1972; Sander, High, Hannay and Sherer, 1997; Livingston, 1986; Kreutzer, Gervasio and Camplair, 1994; Serio, Kreutzer and Witol, 1997), physical health (Oddy, Humphrey and Uttley, 1978; Leathem, Heath and Woolley, 1996), increased levels of stress (Oddy, 1995; Hall, Karzmark, Stevens, Englander, O.Hare and Wright, 1994) and increased social isolation and role change (Leaf, 1993; Frosch et al., 1997; Leathem, Heath and Woolley, 1996). We would expect that the nature and severity of problems experienced by families would differ from family to family. However, Lezak (1996) suggests that although a few families appear strengthened by the difficulties they face, "...most hobble along, crippled and in pain, their problems unrecognised and unending." She paints a gloomy picture but it is one that is written about repeatedly in the literature (Serio, Kreutzer and Witol, 1997; Allen, Linn, Gutierrez and Willer, 1994; Florian, Katz and Lahav, 1989) and I would argue that in recognising and acknowledging this situation it is possible to maximise the therapeutic alliance between the professionals working with the head injured patient and his family.

The family is extremely important in terms of the part they play in rehabilitation and support for the head injured person. Brooks et al. (1986) looked at factors predicting

outcome for the head injured patient. They suggested that some of the variance in their study might be accounted for by the environment in which he lives. Leathem, Heath and Woolley (1996) add support to this view. They report that in their own study the coping strategies of the families involved were critical to the subsequent emotional reaction and adjustment of the head-injured person. Pondsford, Sloan and Snow (1996) suggest that the responses of the family to the head injury may have as significant an impact on the head injured individuals psychological adjustment as the specific disabilities resulting from the injury.

1.2.1 Stress/Burden

Although caring seems fairly commonplace, embedded within ordinary relationships it also appears to result in extraordinary burden (Pearlin, Mullan, Semple and Skaff, 1990). Pearlin et al. conclude from a study of caregiver stress that it is not a single event but rather, "a mix of circumstances, experiences, responses and resources that vary considerably among caregivers and that, consequently, vary in their impact on caregivers health and behaviour".

Grad and Salisbury (1965) incorporate this idea, that individuals react in individual ways, into their view of burden. They distinguish between "subjective" and "objective" burden. The former being the caregivers' emotional reaction to caring, including their perception of strain and the psychological distress they experience. The latter, objective burden, refers to the behaviour changes and practical problems that follow, in this model, from dementia, but could just as easily fit for head injury.

However, this work does not appear to have been built upon in the head injury literature. McKinlay and colleagues appear to be the only researchers to mention Grad and Salisbury's work. In a study of the short-term outcome following head injury, McKinlay et al. (1981) included a measure of carers' burden. In a semi-structured interview, "objective burden" related to the changes observed in the patient and "subjective burden", measured on a seven point scale (1 (no stress) to 7 (severe stress)), related to the amount of strain experienced by the carer. McKinlay et al. (1981) compared subjective burden with the severity of initial head injury

(measured by length of post-traumatic amnesia) and with reports of objective burden. Table 5 below shows the numbers of carers (n =55) reporting low, medium and high levels of stress, three, six and twelve months post injury. (Both objective and subjective burden refer, in McKinlay's work, to the relatives' view of the situation.)

Table 5: Carers' Burden 3, 6 and 12 Months Following Head Injury

Subjective Burden	3 months	6 months	12 months
"low stress" (SB rating 1- 2)	17 (31%)	15 (27%)	14 (26%)
"medium stress" (SB rating 3 – 4)	22 (40%)	22 (40%)	20 (36%)
"high stress" (SB rating 5 – 7)	16 (29%)	18 (33%)	21 (38%)
Total	55	55	55

The figures in Table 5 show that a staggering 70% of carers reported experiencing medium or high levels of stress 3, 6 and 12 months following their relatives' injury. The level of stress also shows no evidence of decline. Brooks et al. (1986) in their 5 year follow up of this group report that 90% of carers (n = 39) continue to report medium and high levels of stress.

a) Relationship of subjective burden to severity of injury

At three months McKinlay et al. (1981) found that there was a significant relationship between subjective burden and severity of initial injury. However, at six months the significance levels were lower and at twelve months the relationship failed to reach significance. This finding, that severity of injury is not directly related to the level of family stress, has been replicated in other studies (Brooks et al. 1986; Livingston, 1987; Novack, Bergquist, Bennett and Gouvier, 1991). Authors have suggested that severity of injury may be a predictive factor in studies of family stress but that there are other contributory factors at work. Brooks et al. (1986)

reported that at one year and at five years post injury the greater the magnitude of behaviour, personality and affective change in the patient, the greater the burden.

b) Relationship of subjective burden to objective burden

As already alluded to, it appears that the types of problems reported by carers are related to their reported levels of subjective burden. McKinlay et al. (1981) report that a trend exists which suggests that the higher the subjective burden the more changes are reported in the patient. This trend reached statistical significance when comparing subjective burden and number of subjective, emotional and disturbed behaviours reported, for example, personality change. This finding is supported by work carried out by Cavallo et al. (1992) who suggest that irritability, mood swings and changed personality are among the variables creating burden in their sample group. Further support for this finding, that only specific types of sequelae relate directly to subjective burden can be found in many other studies (Panting and Merry, 1972; Ponsford, Sloan and Snow, 1996; Jacobs, 1988; Willer, 1991; Brooks and McKinlay, 1983; Allen et al., 1994). Brooks et al. (1986) suggest that despite the significant relationship between levels of stress in the carer and an increase in the negative behaviour in the patient, there is still "..considerable unexplained variance". They suggest that other factors such as the personality of the relative may play a significant role (for further discussion see later).

It seems that a causal relationship between specific behaviour problems and reported stress is often assumed in this literature but at this stage, it does not seem that this can be said conclusively. However, the fact that a relationship (of whatever kind) exists supports the need for intervention and the questionnaire developed by McKinlay and colleagues is to be used in the present study. (For fuller discussion see below.)

Hall, Karzmark, Stevens, Englander, O'Hare and Wright (1994) suggest that comparing measures of caregiver burden or stress across studies is extremely difficult. They emphasise that the measurement of stress is critical. In the studies outlined it is only possible to consider comparing those who have used the same measure and even then Hall et al. suggest that the experience of burden is a complex mix of positive and negative factors which is difficult to equate across studies. Kreutzer, Gervasio and Camplair (1994) also suggest that the definition of burden

used by McKinlay and his colleagues may be "..too broad to provide meaningful measures of specific distress".

It had been suggested that the concept of stress is too poorly defined out-with the experimental context to work with usefully and much of the research in this area is moving towards investigating psychological distress which can be measured in a more defined and replicable manner. The current study is in line with this trend.

1.2.2 Distress

More recently studies have begun to move away from measures of subjective burden towards the use of more standardised questionnaires and the measure of psychological distress, for example, anxiety and/or depression.

Livingston (1987) asked relatives of a group of individuals with minor and severe head injury to complete the General Health Questionnaire (GHQ), the Leeds Scale (both to assess psychological symptoms), the Social Adjustment Schedule and a perceived burden scale. He found that in the year following severe head injury at least one third of relatives were experiencing significant anxiety as measured by the Leeds Scale ("caseness level" >7). Livingston did not record significant levels of depression in the carers in his study. This seems to be in contrast to later studies (Linn et al., 1994, Kreutzer, Gervasio and Camplair, 1994a). However, Livingston's study only looked at relatives in the first year post injury and it may be that they have yet to realise the full extent of the changes in their relative as highlighted in follow up studies up to 25 years post injury (Klonoff, Clark and Klonoff, 1993).

Linn et al. (1994) studied 60 individuals with traumatic brain injury and their spouses 1 to 7+ years post injury. They found that both the head injured individuals and their spouses reported both depression and anxiety. Seventy percent or more in each group had at least mild depression, while fifty percent or more showed increased levels of anxiety.

Kreutzer, Gervasio and Camplair (1994a) also found that forty-seven percent of the carers in their study exceeded criteria for clinically significant levels of emotional distress. Breaking these figures down, they found twenty-three percent depression and thirty-two percent anxiety on the subscales of the Brief Symptom Inventory (BSI). Interestingly, the greatest proportions of elevated scores were on the

Obsessive-Compulsive and Psychoticism scales of the BSI. A closer look at the participants responses, however, revealed that they were responding to items which were suggestive of increased stress levels, for example, concentration problems, feelings of isolation and of being overwhelmed.

More recently, Sander, High, Hannay and Sherer (1997) have attempted to look at predictors of psychological health in carers. They looked at the contribution of subjective burden, coping style and social support on psychological distress. Although not clearly stated, it appears from Sander et al.'s data that carers 0 to 6 months post injury and 6 months to 1.5 years post injury are experiencing clinically significant levels of distress (as measured by the GHQ). They conclude that in terms of,

a) subjective burden – the higher the caregivers' burden the greater the amount of emotional distress experienced
b) coping style – the greater the use of emotion-focussed coping the greater the psychological distress evident in the responses in the GHQ (see later for fuller discussion)
c) social support – greater satisfaction with social support (not actual amount of support) was related to less emotional distress.

1.2.3 Role Change and Social Functioning

A small number of studies over the past two or three years have begun to look at role change and social functioning in carers and families of individuals with a head injury. A role can be defined as, "a function or part played in life or in any event" (Chambers Concise Dictionary). Leathem, Health and Wooley (1996) developed the Role Change Questionnaire that was devised to identify the types of role changes experienced by the carers and the degree of these changes. The questions are divided into four areas, "household activities", "finances", "social life" and "relationships". (Although "work" was not defined as a separate section it appears to be covered in the questions related to the other four sections.) Carers in their study indicated most change in the area of relationships i.e. their relationship with the head-injured person. This included changes in communication, co-operation and closeness. This was

followed by changes in the "social" area that encompassed issues such as going out socially and spending time alone with the head-injured person.

Kozloff (1987) suggests that although initially the family and friends of the head injured individual offer their support, as time post injury increases, fewer non-related people attempt to meet the head injured persons needs. This therefore means that family members serve multiple functions for the head injured person.

Frosch et al. (1997) also conducted a study to identify the effects of traumatic head injury on the roles of caregivers. They used the Role Checklist (Barris, Oakley and Kielhofner, 1987, reproduced in Frosch et al. 1997) to identify role changes in this group. Findings highlighted a trend between the number of role changes reported by the carers and the present behavioural effects of the head-injured individual on the carer. As the number of behaviours reported increased so did the number of role changes. Frosch et al. (1997) suggest that role change, i.e. loss or gain of roles, occurs as part of the normal development process within a family but it may be disrupted by an event such as a head injury. Role change, as identified both by Leathem et al. (1996) and Frosch et al. (1997), may therefore lead to the caregiver being unable to function as effectively in his/her existing roles.

1.2.4 Carer Characteristics

There appears to be evidence from a number of studies which suggests that wives and mothers (the most common carers) differ in the burden and distress they experience (Florian, Katz and Lahav, 1989). There have been two main explanations put forward to explain this.

a) Mothers are more accepting of their child's childish and dependent behaviour. Wives, on the other hand, find it difficult to incorporate this type of relationship into the marital relationship (Florian, Katz and Lahav, 1989).
b) Parents can support each other whereas the wife has to deal with the situation herself (Panting and Merry, 1972).

However, Allen, Linn, Guitierrez and Willer (1994) report that **both** parents and spouses of individuals with head injuries live with significant burden and do not differ in this. This finding replicates that of Livingston, Brooks and Bond (1985) who found no significant difference in perceived burden of wives and mothers and no significant difference in terms of reported psychiatric symptomatology.

Lezak (1988) and Miller (1991) elaborate on this and suggest that parents' problems include:

- Realisation that caring for the child may never end and their hopes for that child dashed.
- The mother is likely to become the focus of competition for attention from the other siblings and from her husband.
- Conflicts may result between the parents regarding the best way to help their child.

In fact, Lezak (1988) reports that it is not unusual for marriages to break down within one or two years post injury.

The types of difficulties experienced by the spouse include:

- Loss of an intimate and sexual relationship and their chief source of support.
- Loss of social contacts because he/she has to care for partner and run the household.
- They become the targets for their partner's anger and fears.
- They feel tied by responsibility, both for their family and by a fear of social reaction if they were to separate.

1.2.5 Summary

Much of the literature investigating outcome following head injury indicates that those who survive (particularly those with severe head injury, but also those with moderate and mild injuries) encounter impairments in physical, cognitive, emotional, behavioural and social well being. In the months and years following head injury the individual may return to physical fitness but other a range of other impairments can remain (often known as the "hidden disability").

The family of the head-injured person often has the responsibility for care following the individual's discharge from hospital. Researchers have consistently found

increased levels of stress and distress in this population as they attempt to adapt to the situation they find themselves in following such a catastrophic event (Peters, Stambrook, Moore and Esses, 1990).

1.3.0 COPING

People cope daily with many different problems. The issue of coping usually comes to the fore in the context of a serious or major life event. Coping efforts are influenced both by characteristics of the person and characteristics of the situation in which he/she is coping. A difference in emphasis on either of these factors leads to two broadly opposed ways of describing how people manage in their environment. Emphasis on personal as opposed to situational factors and a belief that particular coping strategies are a reflection of personality leads some to be more trait (or style) oriented. In contrast, emphasis on situational as opposed to personal factors, that is, a belief that coping strategies change with the situational context, lead some to have a more process (or situation) oriented stance (Compas, Worsham and Sydney, 1997, Lazarus, 1993, Singer, 1984). Singer (1984) suggests that these different views have been voiced in psychology for decades and it is unlikely that the issue will be settled within the smaller field of coping. However, he also argues that one's choice of view has important implications, in that the situational perspective is the only one, in his view, that offers promise "for therapeutic effectiveness".

The most commonly used classification of coping strategies (which comes from the process model) is that proposed by Folkman and Lazarus (Lazarus, 1993). This divides strategies into "problem focussed" and "emotion focussed". Compas, Worsham and Sydney (1997) suggest that later, seemingly diverse, models of coping, all emphasise this basic distinction.

- Problem focussed coping involves practical problem solving attempts to manage the perceived stress arising from the person, environment, or relationship between the two. More simply put, doing something about the source of stress.
- Emotion focussed coping (or emotional regulation) can be seen a) as direct management of the negative emotional response (distress) associated with the

situation and/or, b) attempts to alter ones perception of the situation (Oddy, 1995., Comaps, Worsham and Sydney, 1997, Singer, 1984, Lazarus, 1993; Carver, Scheier and Weintraub, 1989)

Problem focussed coping tends to predominate when people feel that something constructive can be done and emotion focussed coping occurs when people feel that the situation is one to be endured (Carver, Scheier and Weintraub, 1989). Research has suggested that emotion focussed coping is related to higher levels of burden and depression and problem focused coping has been related to lower levels of burden and to positive affect (Saad et al. 1995; Sander et al. 1997). This has led to the assumption that emotion focussed coping is ineffective. However, Lazarus (1993) emphasises that in certain circumstances rational problem solving efforts can be counterproductive and "even likely to result in chronic distress when they fail". In circumstances where nothing can be done to improve the situation, he suggests that emotion focussed coping would therefore be the best choice. Although this important distinction between problem focussed and emotion focussed coping seems easily distinguishable in principle, Carver, Scheier and Weintraub (1989) suggest that it is too simple. They report that research on responses to the Ways of Coping Scale (Folkman and Lazarus, 1980) which was designed to measure the two factors, shows several factors rather than only two. As a result Carver et al. developed their own measure of coping, the COPE, which is used in the present study.

The COPE is based both on previous research and theoretical models (i.e. Lazarus' model of stress and a model of behavioural regulation developed by the authors (Carver, Scheier and Weintraub, 1989)). The authors suggest that the COPE meets the three main problems identified in the existing measures i.e. the diversity of measures, the lack of item clarity and an empirical (rather than a theoretical) basis. They outline 12 separate factors of coping and emphasise that the COPE is designed to distinguish each coping quality as well as possible from other coping qualities (see later).

In spite of Carver et al.'s findings, the emotion focussed/problem focussed coping distinction continues to feature in much of the literature in this area (Moore and Stambrook, 1992; Sander, High, Hannay and Sherer, 1997).

1.3.1 Coping with Caring

There has been a great deal of work done recently investigating how carers cope with caregiving. Much of this work has focussed on carers of individuals with dementia. Saad et al. (1995) used the Carer's Stress Scale (Pearlin et al., 1990) to assess various components of the coping/stress model in carers of dementia sufferers. They found that coping strategies were "important mediators of depression" amongst carers living with a dementia sufferer. They found that those carers who used more active coping strategies experienced less depression. This suggests a problem focussed approach although Saad et al. do not appear to give a definition of "active".

Matson (1994) studied coping in carers of stroke patients and carers of confused older people. He found "non – confronting" coping (for example, confiding in someone, keeping busy) was positively associated with stress and depression (as measured by a symptom rating scale, the Beck Depression Inventory and a difficult feelings scale). Tactical coping responses to specific problems (defined by Matson as "attempting to meet and balance the needs of both carer and dependent person in the context of showing respect, empathy and sensitivity towards the dependent person") was negatively associated with stress and depression.

In a recent study, Pakenham, Dadds and Terry (1995) hypothesised that problem focussed coping amongst carers of individuals with HIV would be related to higher levels of adjustment and lower levels of burden. Emotion focussed coping, on the other hand, they suggested would be related to poorer levels of adjustment and higher levels of burden. Although their hypothesis was not strongly supported, findings were in the predicted direction.

Sex Differences in Coping with Caring

Morris, Morris and Britton (1988) report that the wives of dementia sufferers tend to experience a higher degree of subjective burden or distress than husbands. Of the adult children carers, daughters appear to express higher levels of distress that sons. Zarit et al. (1986) suggest that men adopt a more instrumental (or perhaps problem focussed) approach to daily problems.

Summary

It seems from these few studies, then, that when coping with caring, active, problem solving types of coping strategies seem the most effective in reducing psychological distress.

1.3.2 Coping with Caring In Head Injury

A number of recent studies have looked at coping in relation to head injury. Willer, Allen, Liss and Zicht (1991) looked at the problems and coping strategies of husbands and wives with traumatic brain injury and their able-bodied spouses (carers). Women with traumatic brain injury identified spouse and family support as the coping strategy they found most effective. For husbands with traumatic brain injury, being included in family decisions was seen as their most effective coping technique. The able-bodied spouses of women with traumatic brain injury identified "suppressing one's feelings" as the most effective coping strategy. They also added that maintaining a sense of humour helped them cope. Able-bodied wives' top coping strategy was, "to develop a realistic but optimistic outlook". They also felt that participation in support groups and taking time for themselves were useful strategies. Willer et al. conclude that the coping strategies identified for both groups were still expanding many years after the primary incident. It is also interesting to note the differences in coping strategies between men and women in this study that seems to reflect findings in the dementia literature.

Sander, High, Hannay and Sherer (1997) looked at the contribution of coping strategies to psychological health in caregivers. Using Folkman and Lazarus' (1980) Ways of Coping Scale, they found that the more caregivers used emotion focussed coping the greater the psychological distress evident (as measured on the General Health Questionnaire – 60). The use of problem focussed coping was not significantly related to caregivers' psychological distress in this study. Novack, Bergquist, Bennett and Gouvier (1991) found that following a rehabilitation programme carers' levels of anxiety fell and continued at a stable (low) level for the next three months. They conclude that the carers in this study were using the coping strategies learned from the rehabilitation programme effectively. Unfortunately, the authors do not outline the types of strategies learned.

Oddy (1995) outlines some techniques carers can learn to help them cope. He claims that based on the model developed by Lazarus and colleagues two major strategies for coping are suggested.

1. Altering the way the situation is appraised
2. Enhancing one's ability to deal with the situation.

He suggests that altering carers' appraisal of the situation requires the provision of information and enhancing their ability to deal with the situation requires training in behaviour management techniques and the use of rehabilitation by the person for whom they are caring.
The present study builds on Oddy's first suggestion, i.e. the provision of information to carers of individuals with a head injury.

1.3.3 Summary

The findings of studies investigating coping in carers of individuals with a head injury follow a similar pattern to studies looking at coping strategies in carers generally. That is, carers with higher levels of psychological distress tend to use emotion focussed coping strategies and those with lower levels of psychological distress tend to use problem-focussed strategies.

The female carers in Willer, Allen, Liss and Zicht's (1991) study report that participation in support groups was an effective coping strategy. Social Support is often identified in the literature as protecting individuals from illness and psychological distress and in aiding recovery. It is therefore important to look at this area in more detail in relation to carers and head injury.

1.4.0 SOCIAL SUPPORT

Sheridan and Radmacher (1992) define social support as, "the resources provided to us through our interaction with other people" and Langford et al. (1997) define these resources as assistance and protection. Social support includes in its definition a wide range of helping relationships but most of these people are friends and family. Langford et al. (1997) suggest three theoretical foundations upon which the research in social support is based:

a) Social comparison theory
b) Social exchange theory
c) Social competence

Festinger's (1954) social comparison theory is based on the idea that an individual develops his or her self-concept by comparing him or herself to others in a chosen reference group (i.e. people who are similar to themselves). Langford et al. (1997) suggest that social comparison may not be successful, however, without the process of social exchange.

Social exchange or reciprocity simply refers to the giving and receiving of social support. Langford et al (1997) link the third theory, that of social competence, with social comparison and exchange by suggesting that the latter cannot happen without the former. Being competent socially allows for the formation and maintenance of relationships, which in turn allow for social exchange and social comparison to take place.

The literature in this area identifies two prominent models of social support (although some would argue that these are two aspects of social support rather than two distinct models (Sheridan and Radmacher, 1992)). The two models described are the main effect model and the buffering model.

The main effect model involves large social networks that are said to have positive effects on well being that are unrelated to stress. This model is often described as dealing with the structure of social support and measures are derived from a socio-epidemiological paradigm (Ganster and Victor, 1988). Structure includes factors

such as marital status and membership of organisations. According to the main effect model this structure will, "enhance well being no matter what level of stress is experienced." However, it should be noted that having a large support network does not necessarily mean that a person has a large amount of social support.

The buffering model focuses on aspects of social support which, as its name suggests, act as a buffer against the effects of stress. This model focuses on functional rather than structural supports i.e. the qualities of the social relationships. Sheridan and Radmacher (1992), in their summary of the buffering model, suggest three main categories of functional support: instrumental, informational and esteem. Instrumental (or direct) support may reduce stress by providing direct help to solve the problem, for example, giving a loan. Giving people feedback and information about their source of stress defines informational support, and esteem support (or affirmational support) allows a person to feel valued.

Each model has been emphasised by researchers often to the exclusion of the other but Lackner et al.(1994) suggest that each aspect of social support is not isolated from the others and Sheridan and Radmacher (1992) argue that structural supports can also be a source of functional support.

Langford et al. (1997), in an attempt to incorporate the main aspects of both models, suggested that,

> "... without a structure of people (network) with the quality of connectedness (embeddedness) required to generate an atmosphere of helpfulness and protection (social climate) social supportive behaviours cannot occur."

1.4.1 Social Support and Health

Having looked at some of the theoretical models of social support it is important to look at its effect on individuals in a practical sense.

As defined above, social support is about the assistance and protection we gain from our relationships with other people. Much of current research emphasises the centrality of social support to maintenance of health and several studies have linked structural and functional support with mortality. Other studies have linked social

support to prevention of illness and assistance in recovery (Lackner et al., 1994, Cohen and Hoberman, 1983).

In relation to recovery from illness, Kulik and Mahler (1989), found that, following a coronary bypass, individuals who were married and whose spouses visited frequently recovered more quickly than those individuals who were married but whose spouses did not visit frequently.

However, other studies carried out in this area have not found a consistent relationship between social support and outcome. Currently, it appears that the findings in this area are inconclusive.

1.4.2 Social Support and Mental Health

Social support has also been linked to the alleviation of psychological distress (Morris, 1986; Brown, Andrews, Harris Adler and Bridge, 1986; Ganster and Victor, 1988) and lack of social support is frequently believed to contribute to the seeking of professional help by people in distress (Lindsay and Powell, 1994).

Cohen and Hoberman (1983) looked at positive events and social supports as buffers of negative life events. They found that their participants' perceived availability of social support wholly or partly protected them from the negative effects of high levels of stress. Cohen and Hoberman go on to say that the availability of people to bolster the participants self esteem ("self-esteem support") and having people to talk over their problems with appear to be the most effective buffers against depression.

Brown et al. (1986) looked at self esteem and social support as predictors of risk of depression in women with children at home, in the year following a stressor. They concluded that social support at first interview was predictive of depression at second interview. However, they go on to suggest that confiding alone may not be enough and that active emotional support (and a lack of negative response) is also necessary. They conclude that crisis support appears to be of little importance and that the "history" of the support, through it's impact on self esteem, may be the critical element.

Research suggests that mental health is promoted by support from other individuals who share similar characteristics (Lackner et al. 1994). In addition, it has been

shown that network size affects an individual's ability to cope with life threatening or stressful events and the quality of the emotional support modifies the impact of these events.

1.4.3 Social Support and Caring

There has been a great deal of interest in the literature about whether social support has any influence on the burden of caring. Much of the work done in this area has been carried out with carers of individuals with dementia. Gilhooley (1984) looked at the relationship between social support and caregivers well being in a population of carers of dementing relatives. Social support was measured by frequency of contact with family and friends, help from family and friends and satisfaction with that help (structural and functional measures). Gilhooley found that the amount of contact with and help from family and friends was not significantly correlated with supporters' wellbeing (structural). She did, however, find that there was a significant correlation between carers' **satisfaction** with the support they received from friends and family and their psychological well being.

Morris, Morris and Britton (1988) argue that Gilhooley's measures may not be reliable and they suggest that frequency of visits does not equate to the same as effectiveness of support. Morris et al. go on to suggest that in their study, caregivers were less depressed and felt less strain when they received more informal support (as measured by emotional, instrumental and financial help received).

It appears that there is some conflict then in the literature regarding whether the actual amount of support received or the individual's perception of that help is more beneficial. There also appears to be a lack of clarity surrounding the area of measurement (see below).

Another important point to bear in mind when considering the effectiveness of social support is the suggestion in the literature that caregiving frequently leads to a restriction in social activities and consequently to social isolation (see above). In fact, in a study of carers of long term schizophrenia sufferers, Oldridge and Hughes (1992) found that twenty-four percent (six) of carers perceived nobody in their lives who would be a source of support if needed.

These factors, therefore, must all be taken into account when discussing the relatively new research in the field of social support for carers of individuals with head injury.

1.4.4 Social Support and Caring In Head Injury

Over the past decade there has been increasing interest in the social support of individuals with a head injury and their carers. Kozloff (1987) looked at the social networks and support of head injured individuals and suggests that social support has a positive effect on long term recovery from head injury. This finding is supported by Leach et al. (1994) who suggest that social support influences the emotional readjustment of the head injured individual.

Kozloff goes on to emphasise however, that as time goes on there appears to be a reduction in the head injured person's social network and their family take on more roles. Therefore, not only is the head injured person disadvantaged by their loss of social contact, but their caregivers have less time and energy to continue with their own social contacts.

Perhaps as a result of this breakdown of previous networks carers turn to support groups for their social support. In a study by Willer et al. (1991) wives of head injured husbands rated support groups as one of their top five most effective coping strategies. Interestingly, support from family and friends were not among this top five. Willer et al. did not look at carers' satisfaction with the support received from family and friends and this may have been an important issue. Campbell (1988) concluded from her study of support groups for individuals with head injury that these groups did provide some social support but families also required alternative supports.

In contrast to these studies, Hall et al. (1994) report that at six months, one year and two years post injury, caregivers had a median of six close friends and reported frequent contact with these people.

However, again one cannot assume that frequency of contact (as measured by number of visits and telephone calls) and number of relationships is related to effectiveness of and satisfaction with support.

Satisfaction with support appears to be the key to the influence of social support upon psychological well being

Leathen, Heath and Wooley (1996) concluded from their study that, in general, carers' need for support was being met. Both parents and partners of head injured individuals in this study reported that they were satisfied with the support they received. They looked at the correlation between stress (as measured by the Hassles and Uplifts Scale) and social support and found a negative correlation between stress and total types of social support available and total types of supports utilised.

More recently, Sander et al. (1997) have looked at the effects of social support on the psychological health of caregivers in this area. They found that satisfaction with social support (as measured by Sarason's (1983) Social Support Questionnaire, a standardised measure) rather than amount of support received was significantly related to psychological distress. That is, greater satisfaction with social support was related to lower levels of distress in carers.

Although amount of support received is an important issue, it appears that the carers' satisfaction with the support they receive is more important in relation to their levels of psychological distress.

Measurement of social support should therefore include a measure of both amount actually received and the individual's satisfaction with that support. Power, Champion and Aris (1988) suggest that there are a number of factors that should be taken into account when measuring social support. As well as the issue discussed above regarding satisfaction with support, they argue that it is also important to distinguish between structural and functional aspects of support and emotional and practical support. They also suggest that information on over and under provision of support is a helpful measure of "perceived rather than received" support. The Significant Others Scale (SOS) was developed by these authors and is designed to gather information from the client on both their key supporters and the different types of help that they provide (Milne, 1992).

1.4.5 Summary

It appears from the studies outlined above that social support is particularly important when investigating carers ability to deal with the difficult and stressful situation that they find themselves in. It seems that of prime importance is the carers' satisfaction with the support received.

An individual's locus of control is also reported to be of importance when considering his or her ability to deal successfully (or not) with stressful situations.

1.5.0 LOCUS OF CONTROL

Locus of control (LOC) is a construct derived from Rotter's (1954) social learning (or expectancy) theory. The basis of social learning theory is that the likelihood of a behaviour occurring in a given situation is a function of a) reinforcement and, b) the extent to which that reinforcement is valued (Norman and Bennett, 1996; Rotter, 1966). Rotter (1966) argued that past learning creates cognitive expectancies and that these expectancies guide behaviour both on a specific and general level. That is, an individual will have expectancies for particular situations and general expectancies that cut across situations.

Rotter also argued that although the crucial role of reinforcement is well acknowledged as influential in the acquisition of skills and knowledge, the perception of an event as reinforcing differs from person to person. He suggests that one of the determinants of the reaction is,

> "the degree to which the person perceives that the reward follows from or is contingent upon, his own behaviour or attributes versus the degree to which he feels the reward is controlled by forces outside of himself and may occur independently of his own actions."

He went on to develop an Internal-External Scale (which is used in this study) which looks at individual's "beliefs about the world".

Norman and Bennett (1996) summarise some of the early work carried out employing this scale and report that, compared with externals, internals were found to be more likely to attempt to control their environment, take responsibility for their actions and seek out and use information.

1.5.1 Locus of Control and Coping

If research suggests, for example, that internals exert more control over their environment than externals, it seems fair to assume that an individual's locus of control orientation may be related to their reaction in stressful situations and to the coping strategies they employ (Petrosky and Birkimer, 1991, Kraise and Stryker, 1984, Rao, Subbakrishna and Prabhu, 1990).

Krause and Stryker (1984) conclude from their study investigating the buffering role of LOC beliefs on stress and well being, that individuals with internal locus of control beliefs cope more effectively with stress that individuals with external LOC beliefs. That is, the individuals in this study who define events as out with their control are less able to deal effectively with stress that those who define events as within their control.

More recently, Petrosky and Birkimer (1991), using Levensons' I, P and C Scale (Internal, Powerful Others and Chance) as a measure of LOC, found that in their sample, internal LOC was negatively correlated with individuals reporting of depressive symptoms. External LOC (the "chance" and "powerful others" scales) was positively correlated with individuals reporting of depressive symptoms.

It has also been suggested in the literature that LOC and coping style may be related. Carver, Scheirer and Weintraub (1989) report a negative correlation between internal LOC beliefs and coping by focussing on and venting ones emotions. Rao, Subbakrishna and Prabhu (1990) found in their study that LOC beliefs did not appear to be related to an individual's perception and experience of a stressful event. However, they do suggest that LOC beliefs may determine the use of specific coping strategies. For example, individuals in their study with external LOC beliefs reported coping methods that included, "blaming fate" and "feeling others are responsible".

These studies suggest therefore that LOC, psychological symptom reporting and coping styles appear to be in some way related to one another. Internal LOC seems to allow for more problem – focussed coping strategies and individuals with an internal LOC orientation appear to be more effective at dealing with stressful life events.

1.5.2 Locus of Control and Coping In Head Injury

There has been very little research to date in relation to LOC and head injury. Moor and Stambrook (1992) report that external LOC beliefs in head injured individuals were related to poorer outcomes and internal LOC beliefs were associated with better outcome.

There does not appear to be any work in this area with carers of head injured individuals but the research outlined above would suggest that LOC beliefs would be a particularly important factor to investigate along with coping strategies and psychological distress in this population.

Having looked at the areas of coping, social support and locus of control it is now necessary to move on to investigate the effects of giving information to carers.

1.6.0 INFORMATION

Ley (1988) reports that when asked about their satisfaction with medical consultations, "substantial numbers of patients feel dissatisfied with the communications aspect of their clinical encounters". He goes on to say that often telling patients is not enough to inform them and increase their knowledge about their particular medical condition. This may be due to a lack of medical knowledge, which may mean that the patient does not understand and is reluctant to ask questions about what they have been told. Patients' own perception and expectations about the illness may also affect their interpretation of the information they are given (Brumfitt, Atkinson and Greated, 1994).

In the field of head injury, doctors, nursing staff and therapy staff in the ward or rehabilitation unit where their relative is receiving treatment continually communicate vital information to carers and other family members. Given that anxiety plays a major role in information processing and that, according to Ley (1988), patients show poor recall for oral communication and frequently misunderstand what is communicated, it seems reasonable to consider an alternative or supplementary means of communicating this vital information.

Ellis, Hopkin, Leitch and Crofton (1979) reported that when given supplementary written information on discharge from a respiratory unit, patients understanding and recall of information regarding their diagnosis, prognosis, medication and follow up arrangements was much improved.

Ley (1988) reviewed 32 studies that looked at the impact of written information on knowledge regarding medication. He found that 97% of these studies showed an effect.

There has been some interest in this area from researchers investigating pre-surgical anxiety and outcome. Wallace (1986) found that an information booklet given to individuals prior to their undergoing minor elective surgery significantly reduced their levels of stress and improved recovery. Further investigation suggested that patients who were more knowledgeable had fewer worries prior to surgery. Young and Humphrey (1985) also found that patients given a booklet devised to present

cognitive strategies for coping with anxiety had lower levels of anxiety and reported less pain prior to undergoing a hysterectomy.

In an interesting intervention study by Johnston, Gilbert, Partridge and Collins (1992) it appears possible to alter patients perceived control (in this case with regard to physiotherapy for physical disability). This increase was brought about by providing information to the patient prior to their appointment with a physiotherapist. Johnston et al. suggest that, based on previous research, this increase might in turn result in improved progress with recovery.

It seems then that written information improves knowledge and understanding which, in the studies outlined above, led to a reduction in anxiety and an improved outcome for those patients who received it.

1.6.1 Presentation of Information

Ley (1988) suggests that the advantage of written information is that it can be constructed in such a way as to improve understanding and allow coverage of the important points. Brumfitt, Atkinson and Greated (1994) add that it can also be retained to be reread later thereby enhancing memory. Walker, el-Guebaly, Ross and Currie (1992), in a community survey investigating where people turn for help when anxious or stressed, found that reading material was the most commonly used source of help. They conclude that there is a high degree of public acceptance for self-help reading materials.

Turvey (1988) outlines some of the criteria necessary for an effective self-help manual. Factors include:

- Ease of understanding (readability)
- Material that is divided into clearly labelled sections, with summaries of the main points.
- A description of what the intention of the manual is
- Background information about the problem

Turvey lists fifteen criteria in all but suggests that not all factors will be equally important in different settings.

1.6.2 Information and Carers

Brumfitt, Atkinson and Greated (1994) looked at carers' response to written information about acquired communication problems. They found that 69% of carers agreed that written information only or written and verbal information was preferable to only verbal information. Interestingly, they also asked participants if they had read the booklet more than once and 77% reported that they had done.

Toner (1987), in a study similar to the present study, investigated the effectiveness of an information booklet for carers of dementia sufferers. He highlighted that uncertainty is widely recognised as a potential source of stress and therefore written information aimed at reducing that uncertainty might reduce levels of stress. Toner provided 18 carers with an information booklet and measured their levels of distress using the General Health Questionnaire – 28 (GHQ). The results suggest that the provision of written information was associated with a significant decrease in carer distress. At follow up (11 weeks later) GHQ scores continued to show this downward trend. Toner concluded that the effectiveness of the booklet was based on an increase in knowledge and a decrease in feelings of uncertainty rather than any change in the carers' day to day approach to dealing with the difficult behaviour displayed by the dementia sufferers.

1.6.3 Information and Head Injury

Much of the recent literature looking at carers of head injured individuals has emphasised the need for information for families (Livingston, Brooks and Bond, 1985; Eisner and Kreutzer, 1989; Novack, Bergquist, Bennett and Gouvier, 1991; Merrit and Evans, 1990; Serio, Kreutzer and Gervasio, 1995; Junque, Bruria and Mataro, 1997; Kreutzer, Serio and Bergquist, 1994; Kreutzer, Gervasio and Camplair, 1994; Lezak, 1996; Sander, High, Hannay and Sherer, 1997).

However, this is not a new issue. As far back as 1972, researchers noted the importance of giving information to caregivers. Panting and Merry (1972) found that over half of the relatives in their study felt that doctors had not provided sufficient information with regard to prognosis and possible problems. They recommended at that time,

> "...the provision of more detailed prognosis...,with particular emphasis on warning relatives of emotional difficulties which may occur during recovery."

As emphasised above, it is the emotional and behavioural sequelae of head injury that appear to present carers with the most difficulty and lead to increased burden and distress.

Eisner and Kreutzer (1989) emphasise that a proactive approach is necessary in family intervention and the provision of information is important in providing a more therapeutic environment for the patient and in preventing family crises (see also Lezak, 1996 and Junque et al. 1997).

Livingston, Brooks and Bond (1985) found clinically significant levels of anxiety in more than half of the carers in a study. They conclude that there is an obvious need for help and support for the relatives both for himself or herself and for managing the head injured individual.

Kreutzer and his colleagues investigate, in a number of different studies, the needs expressed by families following traumatic brain injury (Kreutzer, Gervasio and Caplair, 1994; Kreutzer, Serio and Bergquist, 1994; Serio, Kreutzer and Gervasio, 1995). In a review of the literature on carers' needs, Kreutzer, Serio and Bergquist (1994) highlight three common themes:

- The carers desire for information about the injury, the treatment and the prognosis
- A desire for clear and honest communication with the professional involved
- A need for psychological support

Using the Family Needs Questionnaire (developed by the authors) they investigate the reported needs of 119 carers participating in their study. Over 90% of the carers reported a need for information regarding their relatives behavioural, physical, cognitive and medical status and information on how best to deal with the difficulties these may present.

Although much of this information may be distressing, Kreutzer et al. (1994) found that respondents wanted honest and complete information. This finding, that carers wanted "no more surprises", was also highlighted by Gentleman, Gilchrist and Neilson (1996 and personal communication). They found, in a survey of head injured patients and their carers that all but one patient and all but one carer said they wanted to be given information about the acute events of the injury, even if some of it was upsetting. Patients and carers in this study also said they wanted information about the long-term outcome of head injury, "even if the news was not good".

Serio, Kreutzer and Gervasio (1995) also highlight the carers' need for emotional support. This was a need most often perceived as unmet in their study.

Kreutzer, Gervasio and Camplair (1994) conclude that professionals should provide caregivers with, "more consistent and realistic information about behavioural difficulties and their likely impact on the family."

Sander, High, Hannay and Sherer (1997) suggest that information focussing on training in stress reduction techniques (as well as information regarding the injury) may well contribute to an alteration in coping techniques, thereby reducing distress.

In summary, it appears that carers of individuals with a head injury are expressing a need for information regarding:

- The injury and its characteristics (Kreutzer, Gervasio and Camplair, 1994; Serio, Kreutzer and Gervasio, 1995)
- How to deal with behavioural and emotional sequelae (Panting and Merry, 1972; Livingston, Brooks and Bond, 1985)
- How to look after themselves (emotional support)(Sander, High, Hannay and Sherer, 1997)

It seems, however, that in spite of the overwhelming consensus that families require information and that it would be beneficial both for the carers and for the head injured individuals (in aiding recovery), no research has looked directly at the effects of providing this information.

1.7.0 Present Study - Aims and Hypotheses

This study aimed to examine psychological distress in carers of individuals with head injury and, unlike previous studies, to investigate the impact on distress of providing written information. The study examined coping style, social support, and locus of control in relation to anxiety and depression. To date, examination of the effects of providing information has received little attention. It is hoped that, by providing information and investigating the individual characteristics of carers, we will be better placed to decide who would most benefit from the provision of information.

1.7.1 Specific Hypotheses

From the literature:

1a. Levels of anxiety will be greater than those in the general population

1b. Levels of depression will be greater than in the general population

2a. Levels of anxiety will not be significantly related to severity of injury or time post injury.

2b. Levels of depression will not be significantly related to severity of injury or time post injury.

3a. Levels of anxiety will be significantly related to Objective Burden.

3b. Levels of depression will be significantly related to Objective Burden.

4a. Levels of anxiety will be less for those individuals who have high levels of social support

4b. Levels of depression will be less for those individuals who have high levels of social support

5a. Levels of anxiety will be less for those individuals who have an internal locus of control orientation.

5b. Levels of depression will be less for those individuals who have an internal locus of control orientation.

6a. Levels of anxiety will be less in those individuals who have an active, problem solving approach to coping.

6b. Levels of depression will be less in those individuals who have an active, problem solving approach to coping.

Experimental Hypotheses:

7. Levels of anxiety will be reduced by the provision of information
8. The reduction in levels of anxiety will be greater where time post injury is less

CHAPTER 2 - METHOD

2.0 Method

2.1 Design

A longitudinal, mixed variable, within and between subject design was used. Each participant was seen twice, with four weeks separating his or her first and second appointment. Participants were placed in one of two groups, those who were caring for someone who was two to nine months post injury and those who were caring for someone who was one year or more post injury.

The Psychiatry/Clinical Psychology Research Ethics Sub-Committee of the Lothian Research Ethics Committee and the Tayside Committee on Medical Research Ethics granted approval for this study to be carried out.

2.2 Pilot Study of Information Booklet

Prior to beginning the study proper it was felt that it would be helpful to give the newly developed information booklet to a small number of carers of head injured individuals. The booklets were given to six carers. They were also given a questionnaire to complete about the booklet (Appendix 1). The questionnaire included questions relating to the readability of the booklet and to whether there was anything excluded that should have been included and anything that was included that may cause distress and therefore should be removed.
The carers were also asked for any other comments that they might have about the booklet.

All six carers returned the questionnaire.

The main findings were as follows:

Question	Response
Is the booklet easy to read?	100% said yes
Is the way the information is presented easy to follow?	100% said yes
Is there any information that should be removed	100% said no
Would this information have been helpful to you?	100% said yes
When would this information have been useful to you?	87% (5) said at discharge 17% (1) said at 6 months post injury

Two of the respondents said that they would have liked to have specific information about seizures and about constipation. However, it was felt that these subjects were not within the scope of the booklet so no alterations were made on this basis.
Comments made included one carer saying that she felt the booklet was, "a big step in the right direction" and another who said that she felt the booklet should be handed to the carer personally and that the carer should be encouraged to read it at the time so that they would know where to go to for information in the future.

2.3 Main Study

2.3.1 Participants

The participants were thirty-three individuals who were the primary carers of patients who had suffered a head injury. Participants were placed in one of two groups depending on the time post injury. The "early" group included carers of patients who had suffered a head injury two to nine months ago (n = 11) and the "late" group included carers of patients who had suffered a head injury one or more years previously (n = 22).

The inclusion criteria were as follows:

Patients:

- Glasgow Coma Scale of 3 – 14
- Aged between 16 and 65 when the injury occurred
- With or without surgery
- With or without epilepsy.

Participants:

- Living with the head injured person for more than one month post injury
- Aged between 16 and 65
- English as first language

The exclusion criteria were as follows:

- A previous head injury
- Longstanding alcohol/substance misuse
- Living at home with carer for less than 1 month post injury

For each group the severity of the head injury was measured using the Glasgow Coma Scale (GCS) noted in the patients case notes. Where possible the lowest recorded GCS score was included. When no GCS score was available, Post Traumatic Amnesia (PTA) was converted into an approximate GCS score (see Chapter 1). If PTA was not available, comments made in the notes, for example, "severe head injury", were converted into an approximate GCS score.

2.4 Measures

Self Report Questionnaires

2.4 (i) General Health Questionnaire

The General Health Questionnaire (GHQ) was designed by Goldberg (1978) to detect non-psychotic psychiatric disorder in people in community and medical settings using a self-report questionnaire. The original version was made up of 60 questions but through cluster and factor analyses 30, 28 and 12 item questionnaires have been produced (the GHQ-28 is the version used here). They are equally valid and reliable. The GHQ is best designed to detect distress of recent onset.

Each item asks whether the respondent has experienced a particular symptom or item of behaviour recently using a four point scale: "less than usual", "no more than usual", "rather more than usual" or "much more than usual".

Scoring the GHQ-28 can be done in one of two ways. It is possible to score the responses in a likert form 0 1 2 3 and have weights assigned to each response, or in the GHQ form, 0011, which, the authors suggest eliminates errors due to "end users" and "middle users".

The GHQ-28 is divided into four scales:

1. Somatic symptoms
2. Anxiety and Insomnia
3. Social Dysfunction
4. Severe Depression

Both of the scoring methods described above were utilised for this study.

2.4 (ii) Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HAD Scale) is a 14 item scale developed by Zigmond and Snaith (1983) to provide a brief state measure of anxiety and depression. It tries to achieve maximum possible separation between concepts of anxiety and depression.

Although the psychometric properties of the HAD Scale are based on a medical out patient population it is recognised as a useful, clinical tool. It is brief and has good face validity. It is developed for use with a non – psychiatric population and is a reliable instrument for screening clinically significant anxiety and depression. There are similarities between the population in my study and the general medical population that the HAD Scale has been standardised with, for example, stress and frequent visits to hospital.

Each item is scored 0-3 yielding a score of 0-21 for both anxiety and depression. The following cut off points are reported:

0 –7	"normal"
8 – 10	"mild"
11 – 14	"moderate"
15 – 21	"severe"

2.4 (iii) Significant Others Scale

The Significant Others Scale (SOS), designed by Power, Champion and Aris (1988), is designed to gather information from the client on both emotional and practical support, actual and ideal. It focuses on perceived rather than on received support. The short SOS is set out in questionnaire format and the authors advocate use of the short form when other measures are to be administered (as in the present study).

The validity of the SOS has been established by concurrent and construct methods. The concurrent validation took the form of assessing three groups (a symptom free group, non-depressed "cases" and "depressed cases") by the GHQ and the SOS. The significant differences between the depressed sample and the two remaining samples on the GHQ and the SOS provided evidence that the SOS could discriminate in a predicted fashion between the groups. Construct validity was indicated through factor analysis.

The scale is also useful as it allows the individual to state his/her own optimum level of support rather than imposing normative values of how much support each person should have (Power et al., 1988).

In order to score this scale it is possible to obtain a Syntax file for use with the statistical package, SPSS for Windows, from the authors. This calculates for each participant

- actual emotional support (AEM)
- actual practical support (APR)
- ideal emotional support (IEM)
- ideal practical support (IPR)

and also

- the discrepancy between scores for actual emotional support and ideal emotional support (DEM)
- the discrepancy between scores for actual practical support and ideal practical support (DPR)

2.4 (iv) COPE

Carver, Scheier and Weintraub (1989), in order to address some of the issues raised in the literature regarding previous coping measures, designed the COPE. The COPE is a sixty item self-administered scale. It is based on previous research and theoretical models, is a comprehensive measure of coping and can be used to look at situational and dispositional coping. Carver et al. (1989) carried out three studies designed to investigate validity. These studies suggest that the COPE consists of 15 distinct and clearly focused aspects of coping and had discriminant validity.
The different aspects include:

Active coping
Seeking Instrumental Social Support
Seeking Emotional Social Support
Suppression of Competing Activities
Positive Reinterpretation and Growth
Denial
Behavioural Disengagement
Focus on and venting of emotions
Planning
Religion
Restraint Coping
Acceptance
Mental Disengagement
Humour
Alcohol/Drug Use

There are separate scores for each of the 15 scales and these are calculated by adding the scores on the four items that make up each scale. Scores range from 4 to 16 for each scale.

2.4 (v) Internal - External Scale

Rotter's (1966) I – E Scale (UK Version) is made up of 25 statements and the respondent is asked to choose which one is more strongly believed. Twenty of the items are "real" items and five are "filler" items. No manual has been written for the I – E Scale, no specific population was targeted and items are applicable to many life settings. Having gone through a sequence of construction steps the I – E is internally consistent and reliable.

Scoring the I – E Scale is relatively straightforward. Responses are scored 1 or 0 based on a key for scoring and the higher the score, the higher the individual is in his locus of control orientation.

2.4 (vi) Symptom Checklist

This 48 item measure is included for the carer to complete regarding the head injured person's health now as compared to before injury. The measure was developed by McKinlay, Brooks and Hickox (1987) and is based on the concept of "objective" burden introduced into the caring literature by Grad and Sainsbury (1963) (see page13). There is also one question relating to "subjective" burden. It was designed specifically for this population and assesses problems reported in the literature or encountered in the authors clinical and research work with head injured patients. (Appendix 2)

The items included cover 7 broad areas:

1. Physical e.g. motor impairments
2. Language e.g. word finding problems
3. Emotional e.g. violence, mood swings
4. Dependence e.g. how much help is required for dressing, etc.
5. Subjective e.g. tiredness
6. Memory e.g. forgetting names or places
7. Behaviour change e.g. childishness

There are also questions relating to the individuals sexual relationships and their leisure and work status.

Unfortunately there is no formal scoring system available for this measure. A score of 0, 1, or 2 was given to each of the questions depending on whether the carer rated the situation as unchanged, rather worse or much worse since injury. Therefore the higher the overall score the higher the "objective" burden measured. Scores could range from zero to seventy-seven.

2.4 (vii) Booklet Questionnaire

A short questionnaire was developed to investigate the carers' response to the information booklet they were given. (Appendix 3) The questionnaire looks at the following areas:

- Readability of booklet i.e. how easy it was to read and follow
- Interest and helpfulness of the booklet
- Areas missed

It also asks the carer to rate when it would have been most useful to receive the information contained in the booklet.

2.5 Neurological and Acute Data

Data relating to the patients' GCS score and information regarding any CT scans and any post injury complications was collected from medical and psychology files.

2.6 Procedure

Patients from two centres in the east of Scotland were approached to be involved in this study.
Participants were identified from a number of different sources.
These included:

- Referrals to Psychology services (both centres)
- Neurosurgical Ward Discharge Book
- Discharges from the Neurorehabilitation Unit
- Database set up by the Consultant Neuropsychologist and the Consultant in Neurorehabilitation.

Access to the acute wards of one centre was not permitted due to ongoing research so individuals from this area were only identified if they had been referred to the Psychology services between 1995 and 1998.
Information regarding the circumstances of the patients injury (i.e. when it happened, how it happened and what happened immediately following the injury) and their lowest recorded Glasgow Coma Scale or length of Post Traumatic Amnesia was noted.
After the patients were identified they were approached by letter (Appendix 4) to request permission to write to their relative/partner. A stamped addressed envelope (SAE) was enclosed for the patients' convenience. If consent was forthcoming potential participants were sent an introductory letter, information sheet and reply form (Appendix 4). A suggested appointment time was included on the reply form. Participants were encouraged in the letter to telephone if they had any questions or if

they would like to take part but the appointment time offered was unsuitable. Alternatively they could return the reply form in the enclosed SAE.

The appointments were arranged in Dundee Royal Infirmary, Astley Ainslie Hospital in Edinburgh or in the person's own home depending on the participant's preference, and lasted forty-five minutes to one hour. (Later in the study participants were also sent the questionnaire pack through the post for their convenience.)

Prior to the assessment beginning the study was again explained and any questions that the person had were answered.

Following the completion of the questionnaires the participant was given the information booklet. They were reminded that this would be followed up by a telephone call a week later to answer any questions they may have and to arrange a suitable time for the second appointment.

Following the initial appointment, the participant's General Practitioner was informed of their involvement in the study. (Appendix 4)

The second appointment followed the same format as the first, including answering any questions that the person had at that time. The participant was asked to complete all the questionnaires a second time except for the I – E Scale. The Booklet Questionnaire was included in the pack of questionnaire at the second appointment.

Following the second appointment, in accordance with the requirements of the ethics committee, GPs were contacted regarding any of those participants whose scores on the various measures of psychological distress reached clinical significance. (Appendix 4)

2.7 Data Analysis

All statistical analyses were run using SPSS for Windows 95, Version 8. Group means and standard deviations were calculated for the brain injured individuals for the severity of injury and time post injury, and for the carers, for objective burden, psychological distress, coping methods, social support and locus of control measures. Relationships between variables were analysed using Pearson product-moment correlations and multiple regression. Paired t-tests were run for comparisons between participants at time one and time two and between group one (early group) and group two (late group) on the various measures.

CHAPTER 3- RESULTS

CHAPTER 3: RESULTS

3.1 Participants

Thirty-four people responded to the invitation to be involved in this study and completed the first section of the questionnaires and received a copy of the booklet. Twenty-seven of these participants also responded to a second set of questionnaires.

Participants were divided into two groups, the "early" group and the "late" group. The early group included those individuals who were caring for a relative who had sustained a head injury two to nine months previously. The late group included those individuals who were caring for a relative who had sustained a head injury over twelve months ago.

One participant from the late group wrote following her receipt of a booklet to say that she could not longer be involved in the study as her involvement was upsetting her husband (the head-injured individual). Another individual from the late group had to be excluded, as she did not live with the head-injured individual at the time of the study.

In all, there were eleven participants who were included in the early group (2 – 9 months post injury) and twenty-two who were included in the late group (12 months or more post injury).

All eleven individuals included in the early group responded to both sets of questionnaires (i.e. at time one and time two). Of the late group, sixteen of the participants responded to both sets of questionnaires.

Table 6 shows the frequency, in both the early and late groups, of male and female participants and the frequency of partners, parents and siblings involved in the study.

Table 6: Frequencies of Male and Female Participants and of Participants Relationship with the Head Injured Individual for Each Group

	Male	Female	Partner	Parent	Sibling
Early Group	1	10	4	7	0
Late Group	5	17	8	13	1
Total	6	27	12	20	1

Severity of Injury and Months Post Injury

For each group the severity of the head injury was measured using the Glasgow Coma Scale (GCS)(Teasdale and Jennett, 1974) noted in the patients' case notes. Where possible the lowest recorded GCS score was included. When no GCS score was available, Post Traumatic Amnesia (PTA) was converted into an approximate GCS score (see Chapter 1). If PTA was not available, comments made in the notes, for example, "severe head injury", were converted into an approximate GCS score. Tables 7 and 8 show the distribution of GCS scores in both the early and late group respectively. Tables 7 and 8 also show the range of months post injury for both groups.

Table 7: Summary of Severity of Injury (as measured by the Glasgow Coma Scale) and Months Post Injury for the Early Group

Early Group	N	Minimum	Maximum	Mean (Std. Dev.)
Glasgow Coma Scale	11	3.0	14.0	7.0 (4.3)
Months Post Injury	11	3.0	9.0	6.5 (2.3)

Table 8: Summary of Severity of Injury (as measured by the Glasgow Coma Scale) and Months Post Injury for the Late Group

Late Group	N	Minimum	Maximum	Mean (Std. Dev.)
Glasgow Coma Scale	21	3.0	13.0	6.9 (2.8)
Months Post Injury	21	12.0	98.0	32.3 (21.7)

A between groups t- test was conducted to determine whether or not there were any significant differences between the Glasgow Coma Scale scores in each group (see Table 9).

Table 9: T-Test between Glasgow Coma Scale Scores In the Early Group and the Late Group

	t	df	Sig.
Glasgow Coma Scale Early Group and Late Group	.038	30	.970 (NS)

The results in Table 9 show that there is no significant difference between the Glasgow Coma Scale scores in each group.

Symptom Checklist (McKinlay, Brooks and Hickox, 1987) (Appendix 2)

Participants completed a questionnaire that investigates the physical, emotional and behavioural changes that frequently occur following a head injury (The Symptom Checklist). Tables 10 and 11 show a summary of the participants overall score on this measure at time one and time two. (The overall score is called the "Objective Burden".)

Table 10: Summary of Scores on the Symptom Checklist for Participants in the Early and Late Group at Time 1.

	N	Minimum	Maximum	Mean (Std. Dev.)
Early Group	11	0.0	48.0	26.4 (14.3)
Late Group	22	2.0	67.0	30.2 (17.7)

Table 11: Summary of Scores on the Symptom Checklist for Participants in the Early and Late Group at Time 2.

	N	Minimum	Maximum	Mean (Std. Dev.)
Early Group	10	0.0	52.0	29.4 (16.8)
Late Group	14	9.0	65.0	32.28 (19.85)

A within group t-test was conducted for each group to establish whether or not the means at time one and time two were significantly different (see Tables 12 and 13).

Table 12: Within Group T-Test of Symptom Scores at Time 1 and Time 2 for Early Group

		N	Mean (Std. Dev.)	Std. Error Mean			t	df	Sig. (2-tailed)
Pair 1	Symptom 1	11	26.4 (14.3)	4.3	Pair 1	Symptom 1 & Symptom 2	1.1	10	.289 (NS)
	Symptom 2	11	29.4 (16.0)	4.8					

Table 13: Within Group T-Test of Symptom Scores at Time 1 and Time 2 for Late Group

		N	Mean (Std. Dev.)	Std. Error Mean			t	df	Sig (2-tailed)
Pair 1	Symptom 1	16	32.0 (19.3)	4.8	Pair 2	Symptom 1 & Symptom 2	.15	15	.885 (NS)
	Symptom 2	16	31.8 (20.3)	5.1					

The results shown in Tables 12 and 13 suggest that there is not a significant change in participants responses, in either group, to the questions regarding the physical, emotional and behavioural difficulties of the person they are caring for from time one to time two.

A between groups t-test was performed to examine whether or not there was any difference in means from time one to time two. Table 14 shows that the results of this analysis.

Table 14: T-Test between Symptom Checklist Scores In Early Group and Late Group at Time 1 and Time 2.

	t	df	Sig
Symptoms at Time One & Symptoms at Time Two	.63	31	.534 (NS)

The results in Table 14 show that there is no significant difference between the Symptom Checklist scores from time one to time two for both groups.

3.1.1 Summary

The two groups, early and late, did not differ significantly in terms of the severity of injury or in terms of the physical, behavioural and emotional symptoms attributed by the carer to the patient. The above results (Tables 12 and 13) suggest that the head injured persons physical, emotional and behavioural difficulties changed little between time one and time two. Tables 7, 8 and 10 also highlight the range of patients' GCS scores and symptoms.

3.2 Hypotheses from the Literature

Previous research suggests that in this population, carers psychological distress levels are high regardless of the severity of the injury sustained by their relative or the number of months post injury. Much of the literature in this area, however, has looked only at psychological distress as a single variable. In this study anxiety and depression were investigated separately.

3.2.1a Hypothesis 1a: Levels of Anxiety In Carers Will Be Greater Than Those in the General Population

The literature suggests that the prevalence rate for anxiety in the general population is between three and six percent (Weissman and Merikangas, 1986). Eight out of the eleven participants (72%) in the early group were anxious at the beginning of the study to some degree i.e. score over seven on the HADS Anxiety Scale. Using the same criteria, fourteen out of the twenty-two participants (64%) in the late group were anxious to some degree at the beginning of the study.

Although this is a rather crude comparison it does highlight that the participants in this group were significantly more anxious than those in the general population.

3.2.1b Hypothesis 1b: Levels of Depression In Carers Will Be Greater Than Those in the General Population

Studies of GP patient populations give estimates of prevalence for major depression around five percent (Blackburn and Davidson, 1995).
In this study, four of the eleven participants (36%) in the early group were depressed at the beginning of the study to some degree i.e. score over seven on the HADS Depression Scale.
Eight of the twenty-two participants (36%) in the late group scored over seven on the HADS Depression Scale at time one.

Summary of Hypothesis 1a and 1b

By comparing the percentage number of anxious and depressed participants with the number found in the general population it is possible to see that this group of carers report a much higher incidence of anxious and depressive symptomatology.

3.2.2a Hypothesis 2a: Levels of Anxiety Will Not Be Significantly Related To Severity of Injury or to Time Post Injury.

Previous research suggests that severity of injury and the number of months post injury do not show significant associations with carer burden and are therefore unlikely to be useful predictive variables. Much of this research has been carried out using a seven or ten point scale to measure burden. The present study uses the GHQ-28 and the HADS Scale to investigate any association between severity of injury and number of months post injury with anxiety and depression.
Results below are reported for both the GHQ and the Hospital Anxiety and Depression Scale (HADS). (The General Health Questionnaire-28 (GHQ) was also used in this study in order to allow for comparisons to be drawn with previous literature.)

Tables 15 and 16 show the results of correlations calculated between GHQ-28 scores and a) severity of injury (as measured by the Glasgow Coma Scale), and b) the number of months post injury. As no direction was hypothesised the analysis is two-tailed.

Table 15: Correlation between GHQ Scores and Severity of Injury at Time 1

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (2-tailed)
GHQ	33	32.5 (16.8)	-.17	.342 (NS)
Glasgow Coma Scale	32	7.0 (3.3)		

The results in Table 15 show that there does not appear to be a relationship between severity of injury and psychological distress as measured by the GHQ-28. This finding is in line with the literature.

Table 16: Correlation between GHQ Scores and Time Post Injury at Time 1

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (2-tailed)
GHQ	33	32.5 (16.8)	.36	<0.05
Number of Months Post Injury	32	23.5 (21.5)		

The results in Table 16 show a significant relationship between the psychological distress reported by these carers and the number of months post injury. This finding appears contrary to previous findings where researchers report no significant relationship between time post injury and psychological distress.

As the HADS was also used in this study it is possible to look at participants levels of anxiety and depression separately to investigate this finding further.

In order to investigate whether anxiety is related to severity of injury or time post injury for the participants in this study the following correlations were used:

- between participants anxiety scores and the severity of injury (Table 17)
- between participants anxiety scores and the number of months post injury (Table 18)

Table 17: Correlation of Participants' Anxiety with the Severity of Injury

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (2-tailed)
HADS Anxiety	33	9.8 (5.1)	-.21	.254 (NS)
Glasgow Coma Scale	33	6.9 (3.3)		

Table 17 shows that there is a negative Pearson correlation between participant's anxiety and severity of injury. However, this result is not significant.

Table 18 shows the second correlation, between participants' anxiety scores and the number of months post injury.

Table 18: Correlation of Participants' Anxiety with Time Post Injury

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (2-tailed)
HADS Anxiety	33	9.8 (5.1)	.19	.285 (NS)
Number of Months Post Injury	32	23.5 (21.5)		

The results in Table 18 show that there is not a significant relationship between participants' anxiety in this study, and months post injury.

3.2.2b Hypothesis 2b: Levels of Depression Will Not Be Significantly Related to Severity of Injury or Number of Months Post Injury

This hypothesis suggests that depression will not be related to severity of injury, as measured by the GCS, or number of months post injury. A correlational design was used to investigate

- relationship between participants depression scores and severity of injury (Table 19)
- relationship between participants depression scores and number of months post injury (Table 20)

Table 19: Correlation of Participants' Depression with Severity of Injury

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (2-tailed)
HADS Depression	33	6.2 (4.4)	-.05	.793 (NS)
Glasgow Coma Scale	32	6.9 (3.3)		

There is not a significant correlation between participants' depression scores and severity of injury, as shown in Table 19.

Table 20 shows the correlation between participants' depression scores from the HADS and the number of months post injury.

Table 20: Correlation between Participants' Depression Scores and the Number of Months Post Injury

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (2-tailed)
HADS Depression	33	6.2 (4.4)	.53	<0.005
Number of Months Post Injury	32	23.5 (21.5)		

The positive correlation shown here in Table 20 indicates that the longer time post injury is associated with higher levels of depression and this relationship is highly significant contrary to the expectations derived from the literature. As there was a similar number of participants in each group who reported some depressive symptomatology this finding was investigated further (see Figure 1).

Figure 1: HADS Depression Scores Against Number of Months Post Injury

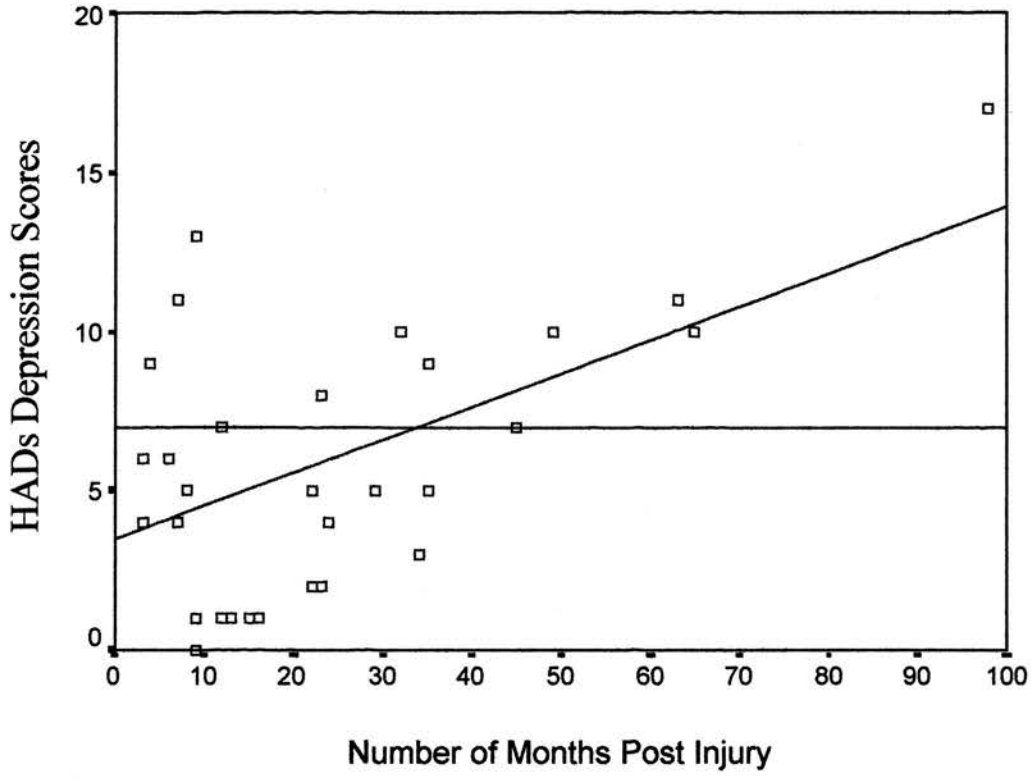

Figure 1 shows that when participants' HADS Depression scores are plotted against months post injury there does appear to be a relationship. However, this finding may be the result of:

- an uneven distribution of numbers in each group (there are twice as many participants in the late group as in the early group)
- the wide range time post injury
- the wide range of responses given (as shown by the large standard deviation (see Table 20)).

If the responses of the early group an the late group are investigated separately it would appear that the first of these suggestions, that the numbers in the late group are greater, would be the most likely explanation for this finding.

Clinically, it is also important to note that the majority of responses fell below eleven, (scores above which would suggest moderate or severe depression). This suggests that participants are only showing a mild elevation in their scores. The majority of participants in this study were not clinically depressed.

Summary of Hypotheses 2a and 2b

As a result of looking at participants' anxiety and depression separately it is possible to note a difference in responses. Neither anxiety nor depression is significantly related to the severity of injury (see Tables 17 and 19). Table 20 shows that depression is significantly related to number of months post injury but given the limitations of numbers in this study and the wide range of months post injury this finding requires replication.

It is only possible to conclude then that part of the hypothesis was confirmed. Severity of injury showed no association with anxiety or depression in the present study. As a result no measure of severity of injury was entered into the regression analysis.

3.2.3a Hypothesis 3a: Levels of Anxiety Will Be Significantly Related to Objective Burden

Some researchers in this area suggest that "Objective Burden", that is, the physical, behavioural and emotional changes that have occurred in the head injured individual, serves as a more effective predictor of psychological distress than severity of injury or months post injury. In the present study, participants' Objective Burden was measured using the Symptom Checklist designed by McKinlay, Brooks and Hickox (1987). As an initial step towards investigating the influence of Objective Burden on participants' anxiety and depression, the relationship between these variables is considered. Later in this chapter further investigations will be carried out using this variable to look at its predictive value (see Section 3.4).

Table 21 shows the correlation between participants' anxiety scores on the HADS and their scores on the Symptom Checklist.

Table 21: Correlation between Participants' Anxiety and Their Objective Burden

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (1-tailed)
HADS Anxiety	33	9.8 (5.1)	.44	<0.01
Objective Burden	33	28.9 (16.5)		

Table 21 shows that there is a significant relationship between participants anxiety scores and their reports of physical, emotional and behavioural changes in the head injured individual they are caring for.

If each group is taken individually, a similar pattern emerges. In both groups, a relationship emerges between anxiety and objective burden (early group, $r = 0.59$, $p<0.05$, 1 tailed, late group, $r = 0.44$, $p<0.05$, 1 tailed).

3.2.3b Hypothesis 3b: Levels of Depression Will Be Significantly Related to Objective Burden

There does not appear to be a consensus in the literature regarding the influence of Objective Burden on participants' levels of depression. To investigate further whether or not a relationship exists between carers' depression and objective burden, a correlation was carried out (see Table 22).

Table 22: Correlation Between Participants' Depression Score and Their Objective Burden Score.

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (1-tailed)
HADS Depression	33	6.2 (4.4)	.67	<0.001
Objective Burden	33	28.9 (16.5)		

Table 22 shows a very strong correlation between participants' depression scores and their Objective Burden scores.

If the two groups are investigated separately a similar picture emerges. In both groups, early and late, there is a significant correlation between depression scores and objective burden (early group, $r = 0.67$, $p<0.05$ and in the late group, $r = 0.68$, $p<0.001$, 1 tailed).

Summary of Hypotheses 3a and 3b

The literature suggests that there will be a significant relationship between participants' anxiety and depression scores and their Objective Burden. Tables 21 and 22 highlight that there is a significant relationship between these variables and analysis of each group separately suggests that this relationship holds regardless of time post injury.

Hypothesis 3a and 3b are therefore confirmed.

3.2.4a Hypothesis 4a: Levels of Anxiety Will Be Lower For Those Individuals Who Have High Levels Of Social Support

In order to investigate the influence of social support on participants' anxiety scores, it was first necessary to calculate from the Significant Others Scale (SOS):

- participants actual levels of emotional support (AEM) and actual levels of practical support (APR)
- participants ideal levels of emotional support (IEM) and ideal levels of practical support (IPR)
- the discrepancy between participants actual emotional support and their ideal emotional support (DEM) and their actual practical support and their ideal practical support (DPR)

The literature would suggest that the smaller the discrepancy between actual and ideal social support, the lower the levels of anxiety should be. In order to investigate this a Pearson Correlation was calculated between participants anxiety scores and their actual emotional and practical support and their discrepancy scores (see Tables 23 and 24).

Table 23: Correlation between Participants' Anxiety Scores and Actual Emotional Support and the Discrepancy Between Actual and Ideal Support

	N	Mean (Std. Dev)	Pearson Correlation	Significance (1-tailed)
HADS Anxiety	33	9.8 (5.1)		
Actual Emotional Support	33	4.9 (1.1)	-.18	.149 (NS)
Discrepancy between Actual and Ideal Emotional Support	33	1.2 (0.8)	.15	.204 (NS)

Table 24: Correlation Between Participants' Anxiety Scores and Actual Practical Support and the Discrepancy Between Actual and Ideal Support

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (1-tailed)
HADS Anxiety	33	9.8 (5.1)		
Actual Practical Support	33	4.6 (1.1)	-.42	<0.01
Discrepancy between Actual and Ideal Practical Support	33	1.2 (0.9)	.40	<0.05

Table 23 shows that there is no significant relationship between participants anxiety scores and their actual emotional support or the discrepancy between their actual and ideal emotional support. However, the results presented in Table 24 show a significant relationship between participants' anxiety scores and their actual practical support ($r = -0.42$, $p<0.01$) and the discrepancy between their actual and ideal practical support ($r =0.40$, $p<0.05$).

3.2.4b Hypothesis 4b: Levels of Depression Will Be Lower for those Individuals Who Have High Levels Of Social Support

Using the same method as above, participants depression scores were considered in relation to their actual and ideal levels of social support. Tables 25 and 26 show the results of these correlations.

Table 25: Correlation between Participants' Depression Scores and Actual Emotional Support and the Discrepancy between Actual and Ideal Support

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (1-tailed)
HADS Depression	33	6.2 (4.4)		
Actual Emotional Support	33	4.9 (1.1)	-.08	.325 (NS)
Discrepancy between Actual and Ideal Emotional Support	33	1.2 (0.8)	.32	<0.05

Table 26: Correlation between Participants' Depression Scores and Actual Practical Support and the Discrepancy Between Actual and Ideal Support

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (2 Tailed)
HADS Depression	33	6.2 (4.4)		
Actual Practical Support	33	4.6 (1.1)	-.39	<0.05
Discrepancy between actual and ideal practical Support	33	1.2 (0.9)	.53	<0.01

Tables 25 and 26 summarise:

- the correlation between participants depression scores and their actual emotional and practical support and,
- the correlation between participants depression scores and the discrepancy between actual and ideal emotional and practical support.

The results in Table 25 show that there is no significant relationship between participants depression scores and their actual emotional support but that there is a significant relationship between depression scores and their discrepancy score between actual and ideal emotional support ($r = 0.32$, $p<0.05$). Table 26 shows that depression scores are also significantly related to practical support. The relationship between participants' depression and their actual practical support score was significant ($r = -0.039$, $p<0.05$) as was the discrepancy between their actual and ideal practical support ($r = .53$, $p<0.01$).

When both groups are included the results presented suggest that anxiety scores are not associated with emotional support (actual or the discrepancy score) but are associated with actual, and the discrepancy between actual and ideal, practical support. Depression is associated with the discrepancy between actual and ideal emotional support but not with actual emotional support and is also associated with actual and discrepancy scores for practical support.

The literature in this area suggests that as the time post injury increases both head-injured individuals and their carers become more socially isolated. If this were the case we could expect to see differences in the effects of social support on anxiety and depression between the early and late group.

Tables 27 to 34 show the results for each group of the correlations between anxiety and depression and actual emotional and practical support and the discrepancy between actual and ideal emotional and practical support.

Table 27: Correlation between Participants' Anxiety Scores and Actual Emotional Support and the Discrepancy between Actual and Ideal Support In the Early Group

	N	Pearson Correlation	Significance (1-tailed)
HADS Anxiety	11		
Actual Emotional Support	11	-.19	.289 (NS)
Discrepancy Between Actual and Ideal Emotional support	11	.32	.172 (NS)

Table 28: Correlation between Participants' Anxiety Scores and Actual Emotional Support and the Discrepancy Between Actual and Ideal Support In the Late Group

	N	Pearson Correlaton	Significance (1-tailed)
HADS Anxiety	22		
Actual Emotional Support	22	-.20	.181 (NS)
Discrepancy Between actual and Ideal Emotional Support	22	.21	.178 (NS)

Table 29: Correlation between Participants' Anxiety Scores and Actual Practical Support and the Discrepancy Between Actual and Ideal Support In the Early Group

	N	Pearson Correlation	Significance (1-tailed)
HADS Anxiety	11		
Actual Practical Support	11	-.40	.112 (NS)
Discrepancy between Actual and Ideal Practical Support	11	.50	.059 (NS)

Table 30: Correlation between Participants' Anxiety Scores and Actual Practical Support and the Discrepancy Between Actual and Ideal Support In the Late Group

	N	Pearson Correlation	Significance (1-tailed)
HADS Anxiety	22		
Actual Practical Support	22	-.43	<0.05
Discrepancy Between Actual and Ideal Practical Support	22	.40	<0.05

Table 31: Correlation between Participants' Depression Scores and Actual Emotional Support and the Discrepancy Between Actual and Ideal Support In the Early Group

	N	Pearson Correlation	Significance (1-tailed)
HADS Depression	11		
Actual Emotional Support	11	.01	.485 (NS)
Discrepancy Between Actual and Ideal Emotional Support	11	.28	.206 (NS)

Table 32: Correlation between Participants' Depression Scores and Actual Emotional Support and the Discrepancy Between Actual and Ideal Support In the Late Group

	N	Pearson Correlation	Significance (1-tailed)
HADS Depression	22		
Actual Emotional Support	22	-.14	.267 (NS)
Discrepancy Between Actual and Ideal Emotional Support	22	.37	<0.05

Table 33: Correlation between Participants' Depression Scores and Actual Practical Support and the Discrepancy Between Actual and Ideal Support In the Early Group

	N	Pearson Correlation	Significance (1-tailed)
HADS Depression	11		
Actual Practical Support	11	-.25	.227 (NS)
Discrepancy Between Actual and Ideal Practical Support	11	.42	.097 (NS)

Table 34: Correlation between Participants' Depression Scores and Actual Practical Support and the Discrepancy Between Actual and Ideal Support In the Late Group

	N	Pearson Correlation	Significance (1-tailed)
HADS Depression	22		
Actual Practical Support	22	.47	<0.05
Discrepancy Between Actual and Ideal Practical Support	22	.58	<0.01

Summary of Tables 27 to 34

In the early group, that is, participants who have been caring for someone with a head injury for up to nine months, there are no significant relationships between anxiety and depression scores and the discrepancy between actual and ideal emotional or practical support (see Tables 27, 29, 31 and 33). However, in the late

group who have been carers for more than a year, there are significant relationships between the following:

- anxiety scores and actual practical support ($r = -0.43$, $p<0.05$) (see Table 30)
- anxiety scores and the discrepancy between actual and ideal practical support ($r = 0.40$, $p<0.05$)(see Table 30)
- depression scores and the discrepancy between actual and ideal emotional support ($r = 0.37$, $p<0.05$)(see Table 32)
- depression scores and actual practical support ($r=.47$, $p<0.05$) (see Table 34)
- depression scores and the discrepancy between actual and ideal practical support ($r = 0.58$, $p<0.01$)(see Table 34)

It should be noted that the small sample size for the early group may present a problem as their results, although they do not reach significance, are in the same direction as those of the late group in the following areas:

- anxiety scores and the discrepancy between actual and ideal practical support
- depression scores and the discrepancy between actual and ideal practical support

Summary of Hypotheses 4a and 4b

The literature suggests that anxiety and depression scores should be lower if individuals have good social support. If the discrepancy between their ideal and actual support is large then they do not have the social support they require. The above results suggest that, although there is a discrepancy between actual and ideal for both emotional and practical support, this discrepancy is significantly related to anxiety and depression only for practical support. Further investigations suggest that it is primarily in the late group that these significant relationships exist, although the small sample size for the early group may conceal similar relationships.

3.2.5a Hypothesis 5a: Levels of Anxiety Will Be Lower for Those Individuals Who Have an Internal Locus Of Control Orientation

The lower the score on Rotter's (1966) Internal-External Scale, the more internal in locus of control orientation an individual is. Therefore if this hypothesis were to be correct, the IE score would correlated positively with level of anxiety.
A correlational design was adopted to identify any relationship between these two variables. Table 35 shows the results of this correlation.

Table 35: Correlation between Anxiety and Locus of Control

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (1-tailed)
HADS Anxiety	33	9.8 (5.1)	.18	.165 (NS)
IE Scale	33	13.2 (3.2)		

Table 35 shows that there is no significant relationship between participants' locus of control orientation and their anxiety scores in this study.

3.2.5b Hypothesis 5b: Levels of Depression Will Be Lower for those Individuals Who Have An Internal Locus Of Control Orientation

As was outlined above, the lower the score on the IE Scale the more internal an individual is in his or her locus of control orientation. A correlation was carried out to investigate the relationship between depression and locus of control orientation in this population (see Table 36).

Table 36: Correlation between Depression and Locus Of Control Orientation

	N	Mean (Std. Dev.)	Pearson Correlation	Significance (1-tailed)
HADS Depression	33	6.2 (4.4)	.03	.428 (NS)
IE Scale	33	13.2 (3.2)		

The results in Table 36 show that there is not a significant relationship between participants' depression and their locus of control orientation in this population.

Research has also shown that locus of control and coping style may be related (Carver, Scheirer and Weintraub, 1989). In this study, there are no significant correlations (when alpha is set at $p<0.01$) between any of the fifteen coping subscales and participants scores on the Internal-External Scale.

Summary of Hypotheses 5a and 5b

The results given in Tables 35 and 36 show no significant relationship between participants' anxiety or depression and their locus of control orientation. It is not possible in this case to reject the null hypothesis.

3.2.6a Hypothesis 6a: Levels of Anxiety Will Be Lower for those Individuals Who Adopt an Active, Problem-solving Approach to Coping

The COPE questionnaire is divided up into two sections, "general", i.e. how the respondent generally copes in difficult situations, and "specific", i.e. how the respondent copes with the situation in which they currently find themselves. The present study adopted this procedure and identified the "specific" section as how participants coped with caring for an individual with a head injury. It is important, before going on to investigate the hypothesis any further, to see whether or not participants report any change in their coping, from general to specific. Any change

noted might suggest that participants alter their coping to deal with the particularly difficult situation in which they find themselves. The following tables summarise the paired samples t-tests that were carried out to look at this issue both in the participants as a whole and also within each group.

As the COPE divides into fifteen subsections this means that there are a large number of comparisons in this section. As a result of this and the small sample size, alpha is adjusted to $p<0.01$.

Table 37: Paired Samples T-Test Comparing the Means of General With Specific Coping Responses for the Early Group

PAIRS	t	df	Significance (2-tailed)
G Active Coping & S Active Coping	3.39	10	**<.01**
G Planning & S Planning	2.29	9	.048 (NS)
G Instrumental Social Support & S Instrumental Social Support	2.38	10	.039 (NS)
G Emotional Social Support & S Emotional Social Support	3.21	10	**<.01**
G Suppression & S Suppression	4.90	10	**<.01**
G Religion & S Religion	2.70	10	.022 (NS)
G Positive Reinterpretation & S Positive Reinterpretation	3.71	10	**<.01**
G Restraint & S Restraint	1.15	10	.227 (NS)
G Accept & S Accept	3.06	10	.012 (NS)
G Focus on and Vent Emotions & S Focus on and Vent Emotions	3.02	10	.013 (NS)
G Denial & S Denial	2.54	9	.032 (NS)
G Mental disengagement & S Mental Disengagement	2.70	10	.022 (NS)
G Behavioural Disengagement & S Behavioural Disengagement	2.40	10	.044 (NS)
G Alcohol and Drugs & S Alcohol and Drugs	1.13	10	.285 (NS)
G Humour & S Humour	0.38	10	.709 (NS)

Table 37 shows the significant differences between the responses of participants in the early group on how they cope generally and how they cope in the specific situation in which they currently find themselves. The strategies that show a significant change are:

- active coping
- seeking emotional support

- suppression of competing activities
- positive reinterpretation

Similar t-tests were carried out for the late group (see Table 38).

Table 38: Paired Samples T-Test Comparing the Means of General with Specific Coping Responses for the Late Group

PAIRS	t	df	Significance (2-tailed)
G Active Coping & S Active Coping	2.66	15	.018 (NS)
G Planning & S Planning	2.72	18	.014 (NS)
G Instrumental Social Support & S Instrumental Social Support	2.03	17	.058 (NS)
G Emotional Social Support & S Emotional Social Support	1.95	19	.066 (NS)
G Suppression & S Suppression	2.48	18	.023 (NS)
G Religion & S Religion	1.68	18	.110 (NS)
G Positive Reinterpretation & S Positive Reinterpretation	3.02	16	**<.01**
G Restraint & S Restraint	2.36	17	.030 (NS)
G Accept & S Accept	2.91	18	**<.01**
G Focus on and Vent Emotions & S Focus on and Vent Emotions	1.33	18	.199 (NS)
G Denial & S Denial	1.42	18	.172 (NS)
G Mental disengagement & S Mental Disengagement	2.71	19	.014 (NS)
G Behavioural Disengagement & S Behavioural Disengagement	1.72	18	.103 (NS)
G Alcohol and Drugs & S Alcohol and Drugs	0.94	19	.359 (NS)
G Humour & S Humour	1.32	19	.202 (NS)

Table 38 shows that, for the late group, slightly fewer of the participants' responses seem to change from the general section to the specific section. Whether this is due to their being less aware of any changes in coping because of the time post injury or whether at an earlier stage their coping changed for a short period and they have now returned to their general coping strategies. Table 38 shows that there was a significant change in:

- positive reinterpretation
- acceptance

There are no significant mean differences between the early group and the late group for general or specific coping strategies.

Having established that participants do appear to alter their coping strategies when dealing with a specific stressor, it is now of interest to look at how anxiety and depression are related to the various coping strategies measured by the COPE.
Again, due to the large number of comparisons to be carried out, the alpha was altered to 0.01.

Table 39: Correlation between Anxiety and General Coping Strategies for the Early Group and the Late Group

		N	Pearson Correlation	Significance (2-tailed)
HADS Anxiety				
Active Coping	**E**	11	.40	.230 (NS)
	L	16	.36	.173 (NS)
Planning	**E**	10	.66	.039 (NS)
	L	19	.11	.667 (NS)
Instrumental Social Support	**E**	11	.08	.821 (NS)
	L	18	.05	.844 (NS)
Emotional Social Support	**E**	11	-.12	.730 (NS)
	L	20	.12	.630 (NS)
Suppression	**E**	11	.59	.054 (NS)
	L	19	.28	.241 (NS)
Religion	**E**	11	.30	.374 (NS)
	L	20	.45	.047 (NS)
Positive Reinterpretation	**E**	11	.15	.655 (NS)
	L	17	.22	.389 (NS)
Restraint	**E**	11	.38	.250 (NS)
	L	18	.18	.468 (NS)
Acceptance	**E**	11	.13	.701 (NS)
	L	19	-.25	.311 (NS)
Focus on and vent Emotions	**E**	11	.50	.118 (NS)
	L	19	.55	.015 (NS)
Denial	**E**	11	.61	.045 (NS)
	L	19	.40	.093 (NS)
Mental Disengagement	**E**	11	.02	.963 (NS)
	L	20	-.08	.749 (NS)
Behavioural Disengagement	**E**	11	.52	.105 (NS)
	L	19	.36	.127 (NS)
Alcohol and Drugs	**E**	11	.29	.387 (NS)
	L	20	.28	.240 (NS)
Humour	**E**	11	.49	.122 (NS)
	L	20	.23	.337 (NS)

Table 39 shows that none of the correlations carried out, for the early group or the late group, are significant.

It was, however, considered necessary to carry out this number of correlations as the COPE is most usefully divided into fifteen subscales.

Table 40 shows, for both the early and the late group, the correlations between participants' anxiety and their specific coping strategies

Table 40: Correlation between Anxiety and Specific Coping Strategies for the Early Group and the Late Group

		N	Pearson Correlation	Significance (2-tailed)
HADS Anxiety	**E**			
	L			
Active Coping	**E**	11	.27	.421 (NS)
	L	17	.57	.017 (NS)
Planning	**E**	10	.34	.329 (NS)
	L	20	.28	.224 (NS)
Instrumental Social Support	**E**	11	-.21	.540 (NS)
	L	19	.40	.087 (NS)
Emotional Social Support	**E**	11	-.11	.743 (NS)
	L	21	.52	.016 (NS)
Suppression	**E**	11	.49	.127 (NS)
	L	20	.47	.045 (NS)
Religion	**E**	11	.30	.374 (NS)
	L	20	.45	.047 (NS)
Positive Reinterpretation	**E**	11	.12	.731 (NS)
	L	18	.27	.286 (NS)
Restraint	**E**	11	.24	.486 (NS)
	L	19	.46	.047 (NS)
Acceptance	**E**	11	-.28	.409 (NS)
	L	20	-.13	.578 (NS)
Focus on and Vent Emotions	**E**	11	.47	.144 (NS)
	L	20	.85	**<.001**
Denial	**E**	10	.71	.022 (NS)
	L	20	.42	.069 (NS)
Mental disengagement	**E**	11	.26	.434 (NS)
	L	21	.10	.673 (NS)
Behavioural Disengagement	**E**	11	.64	.034 (NS)
	L	20	.53	.016 (NS)
Alcohol and Drugs	**E**	11	.17	.612 (NS)
	L	21	.34	.133 (NS)
Humour	**E**	11	.01	.969 (NS)
	L	21	.19	.403 (NS)

The results in Table 40 show that there is only one "specific" coping strategy that is significantly correlated with anxiety at the $p<0.001$ level. Focussing on and venting emotions in the late group is significantly related to anxiety.

3.2.6b Hypothesis 6b: Levels of Depression Will Be Lower for those Individuals Who Adopt an Active, Problem-Solving Approach to Coping

In a similar way to the analysis used above in Tables 39 and 40, participants' scores on the depression scale of the HADS were entered into correlations with the general and specific coping strategies.

Table 41: Correlation between Depression and General Coping Strategies for the Early Group and the Late Group

		N	Pearson Correlation	Significance (2-tailed)
HADS Depression				
Active Coping	**E**	11	.27	.471 (NS)
	L	16	-.22	.419 (NS)
Planning	**E**	10	.66	.037 (NS)
	L	19	-.33	.168 (NS)
Instrumental Social Support	**E**	11	.18	.594 (NS)
	L	18	-.47	.048 (NS)
Emotional Social Support	**E**	11	-.02	.950 (NS)
	L	20	-.02	.940 (NS)
Suppression	**E**	11	.55	.078 (NS)
	L	19	-.00	.993 (NS)
Religion	**E**	11	.20	.547 (NS)
	L	19	.20	.417 (NS)
Positive Reinterpretation	**E**	11	.44	.181 (NS)
	L	17	-.18	.495 (NS)
Restraint	**E**	11	.33	.322 (NS)
	L	18	-.02	.947 (NS)
Acceptance	**E**	11	.38	.243 (NS)
	L	19	-.10	.671 (NS)
Focus on and Vent Emotions	**E**	11	.48	.133 (NS)
	L	19	.02	.938 (NS)
Denial	**E**	11	.38	.245 (NS)
	L	19	.49	.035 (NS)
Mental Disengagement	**E**	11	.06	.872 (NS)
	L	20	.08	.746 (NS)
Behavioural Disengagement	**E**	11	.41	.213 (NS)
	L	19	.40	.088 (NS)
Alcohol and Drugs	**E**	11	.14	.681 (NS)
	L	20	-.08	.738 (NS)
Humour	**E**	11	.27	.421 (NS)
	L	20	-.04	.859 (NS)

Table 41 shows that none of the comparisons reach significance at the set alpha level of 0.01.

Table 42: Correlation between Depression and Specific Coping Strategies for the Early Group and the Late Group

		N	Pearson Correlation	Significance (2-tailed)
HADS Depression				
Active Coping	**E**	11	.04	.910 (NS)
	L	17	.14	.585 (NS)
Planning	**E**	10	.09	.812 (NS)
	L	20	-.17	.484 (NS)
Instrumental Social Support	**E**	11	.06	.857 (NS)
	L	19	-.17	.483 (NS)
Emotional Social Support	**E**	11	.02	.942 (NS)
	L	21	.21	.365 (NS)
Suppression	**E**	11	.30	.374 (NS)
	L	20	.13	.575 (NS)
Religion	**E**	11	.14	.673 (NS)
	L	20	.28	.226 (NS)
Positive Reinterpretation	**E**	11	.11	.755 (NS)
	L	18	-.14	.566 (NS)
Restraint	**E**	11	.38	.252 (NS)
	L	19	.24	.332 (NS)
Acceptance	**E**	11	-.24	.473 (NS)
	L	20	-.02	.946 (NS)
Focus on and Vent Emotions	**E**	11	.64	.033 (NS)
	L	20	.31	.185 (NS)
Denial	**E**	10	.43	.212 (NS)
	L	20	.55	.013 (NS)
Mental Disengagement	**E**	11	.46	.157 (NS)
	L	21	.22	.341 (NS)
Behavioural Disengagement	**E**	11	.56	.077 (NS)
	L	20	.60	**<.01**
Alcohol and Drugs	**E**	11	-.03	.926 (NS)
	L	21	.04	.847 (NS)
Humour	**E**	11	-.15	.655 (NS)
	L	19	-.01	.955 (NS)

Table 42 shows that for the early group there are no significant correlations between depression and the various coping strategies. For the late group the relationship between depression and behavioural disengagement as a coping strategy reached significance.

Summary of Hypotheses 6a and 6b

The results in Tables 37 and 38 show that there are significant differences between participants' responses to the question of how they cope in general and how they cope with a difficult situation. Tables 39 to 42 display the results of correlations between anxiety and depression and these responses for both groups. None of the general or specific strategies were significantly correlated with anxiety or depression for the early group. In the late group, focussing on and venting emotions was significantly correlated with anxiety, and behavioural disengagement was significantly correlated with depression.

3.3 Experimental Hypotheses

3.3.1 Hypothesis 7: Levels of Anxiety will Be Reduced by the Provision of Information

The booklet developed for this study contains advice that was aimed at reducing participants' anxiety. Therefore, the analysis is based on the reduction of anxiety as measured by the HADS Anxiety Scale (see Table 44). However, to allow for comparisons with previous literature participants GHQ-28 scores at time one and time two are also reported here (see Table 43).

As a direction was stated in each of the experimental hypotheses it was possible to use 1 tailed t-tests. (As SPSS 8 does not have a 1 tailed function for paired samples t-tests, tables in Greene and D'Oliveira (1982) were used to calculate 1 tailed significance.)

Table 43: Paired Samples T-Test between Means of GHQ at Time 1 and Time 2

		N	Mean (Std. Dev.)	Std. Error Mean			t	df	Sig. (1 tailed)
Pair 1	GHQ 1	27	32.9 (17.4)	3.4	Pair 1	GHQ 1 GHQ 2	1.96	26	<0.05
	GHQ 2	27	29.2 (17.2)	3.3					

The t-test results in Table 43 show that there was a significant decrease in the means of participants' GHQ scores from Time 1 to Time 2. This may be due to a number of factors unrelated to the provision of the information booklet which have not been controlled for, such as an improvement in the head injured individual or the passage of time. However, it is possible to say that this reduction in participants' levels of psychological distress as measured by the GHQ-28 was not due to chance alone.

Table 44: Paired Samples T-Test between Means of HADS Anxiety at Time 1 and Time 2

		N	Mean (Std. Dev.)	Std. Error Mean			t	df	Sig. (1 tailed)
Pair 1	HADS Anxiety 1	27	9.96 (5.01)	1.0	Pair 1	HADA1 – HADA2	1.25	26	.111 (NS)
	HADS Anxiety 2	27	9.20 (5.63)	1.1					

When all the participants are included, as shown in Table 44, there is no significant difference between their HADS Anxiety scores at time one and at time two. It would appear that the GHQ-28 is measuring some change that is not tapped by the HADS Anxiety scale alone.

Summary of Hypothesis 7

When all participants' are investigated together, their scores show a significant decrease on the GHQ-28 from time one to time two ($t = 1.96$, $p<0.05$). However, a similar result is not found for the HADS Anxiety scores.

It is only possible to say then that participants' levels of overall psychological distress (as measured by the GHQ-28) have fallen following the provision of the information booklet. The results do not support the hypothesis, which suggested that participants' anxiety levels would decrease.

3.3.2 Hypothesis 8: The Reduction In Anxiety Will be Greater Where Time Post Injury Is Less

The type of information contained in the information booklet was designed to give carers information regarding their relative's injury, suggest ways that they might respond to problems and advise on ways to look after themselves (basic anxiety management techniques). This type of information, it was felt, would be of greater benefit to those participants in the early group who would be less likely to have fully developed their own ways of dealing with the problems that faced them.

In order to investigate this hypothesis the participants responses in each group were examined separately. The early group will be investigated first:

a) Early Group (n = 11)

As the GHQ showed a significant change for all participants (see above) it will be investigated here along with the HADS.

Figure 2 shows, in graph form, the shift in the early group's GHQ scores from Time one to Time two

Figure 2: GHQ Scores at Time 1 and Time 2 for the Early Group

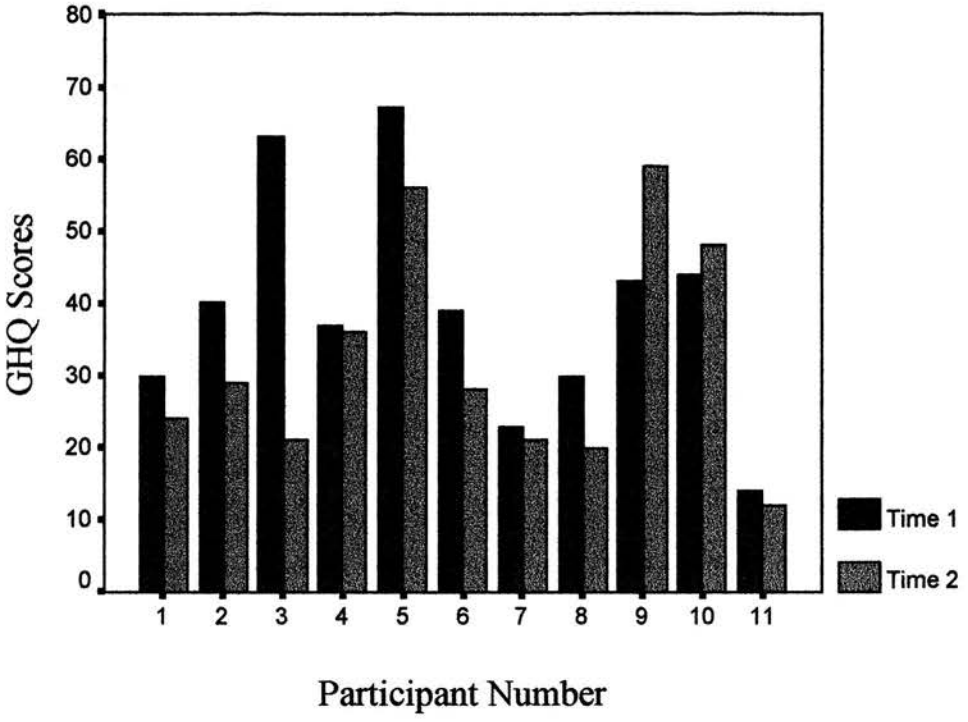

Figure 2 shows that the majority of participants show some decrease in their GHQ scores from time one to time two. Three of the eleven participants show a decrease in scores from above the cut off to below (when the GHQ-28 is scored using the

GHQ method). From a clinical point of view this is important, as participants have moved from being clinically distressed at the start of the study, to being within normal limits at the end of the study.

Table 45 shows the results of a paired t-test, comparing participants' GHQ scores at time one and time two.

Table 45: Paired Samples T-Test between Means of GHQ Scores at Time 1 and Time 2 in Early Group

		N	Mean (Std. Dev.)	Std. Error Mean			t	df	Sig. (1-tailed)
Pair 1	GHQ 1	11	39.09 (15.65)	4.72	Pair 1	GHQ 1 GHQ 2	1.61	10	.69 (NS)
	GHQ 2	11	32.18 (15.66)	4.72					

The results shown in Table 45 indicate that although the findings are in the predicted direction, there is not a significant difference between the means of participants' GHQ scores at time one and time two. However, there were only eleven participants' scores included in this analysis. A larger sample size would be required to draw any conclusions from these results.

Figure 3 shows the change in HAD Anxiety scores from time one to time two for the early group.

Figure 3: HADS Anxiety at Time 1 and Time 2 for the Early Group

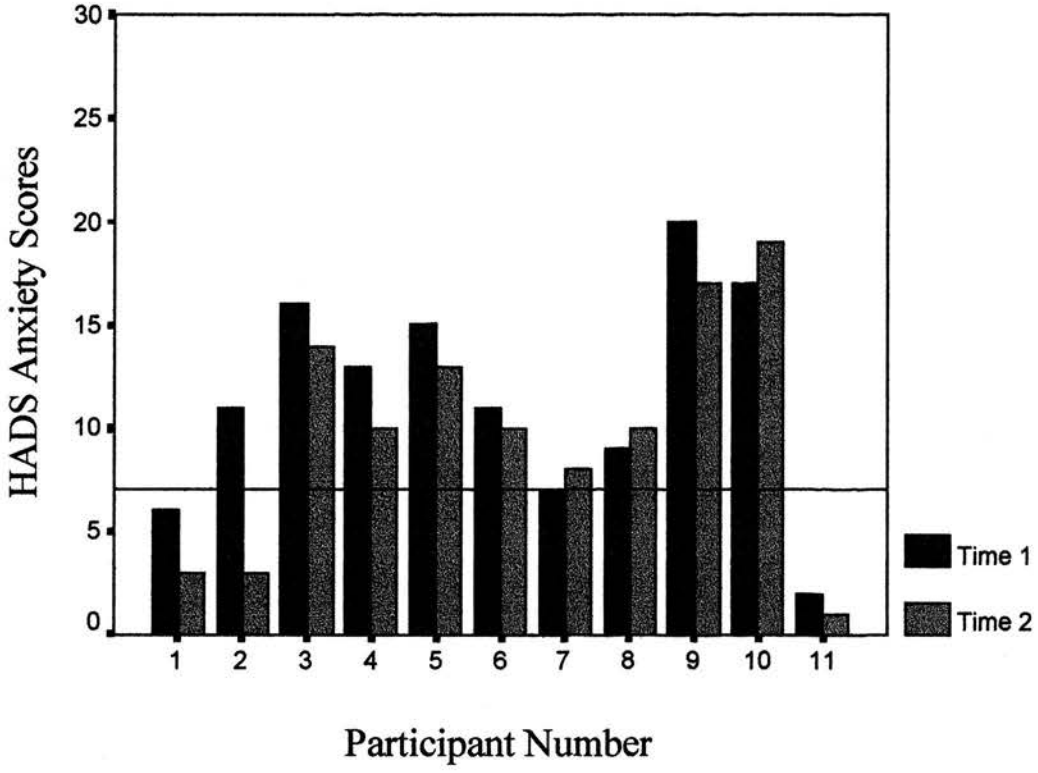

Figure 3 shows that eight of the eleven participants (73%) in this group showed some decrease in their HADS Anxiety score. However, most did not move from above the cut off line to below it.

Table 46 shows the results of a paired samples t-test using the HADS Anxiety Scores at time one and time two.

Table 46: Paired Samples T-Test between Means of HADS Anxiety Scores at Time 1 and Time 2 in Early Group

		N	Mean (Std. Dev.)	Std. Error Mean			t	df	Sig. (1-tailed)
Pair 1	HADS Anxiety 1	11	11.5 (5.34)	1.61	Pair 1	HADS anxiety 1	2.10	10	<0.025
	HADS Anxiety 2	11	9.81 (5.81)	1.75		HADS Anxiety 2			

Table 46 presents a significant result, suggesting that there is a significant difference between participants' HADS Anxiety Scores at time one and time two.

b) Late Group (n = 15)

A similar set of analysis was carried out for the late group, using both participants' GHQ-28 scores (see Table 47) and their HADS Anxiety scores (see Table 48).

Table 47: Paired Samples T-Test between Means of GHQ Scores at Time 1 and Time 2 in Late Group

		N	Mean (Std. Dev.)	Std. Error Mean			t	df	Sig. (1 tailed)
Pair 1	GHQ 1	16	28.75 (17.78)	4.45	Pair 1	GHQ 1 & GHQ 2	1.32	15	.103 (NS)
	GHQ 2	16	27.19 (18.32)	4.58					

Table 47 shows that there is not a significant relationship between participants' GHQ scores at time one and time two for the late group.

Table 48: Paired Samples T-Test between Means of HADS Anxiety Scores at Time 1 and Time 2 in Late Group

		N	Mean (Std. Dev.)	Std. Error Mean			t	df	Sig. (1 tailed)
Pair 1	HADS Anxiety 1	16	8.88 (4.63)	1.16	Pair 1	HADS Anxiety 1	.078	15	.470 (NS)
	HADS Anxiety 2	16	8.81 (5.66)	1.41		HADS Anxiety 2			

The results in Table 48 show that there is also no significant change in HADS Anxiety scores, for the late group, from time one to time two.

Summary of Experimental Hypothesis 2

The analysis described above was carried out to investigate whether or not participants in the early group showed a more significant reduction in anxiety than those participants in the late group. The results suggest that the early group did indeed show a reduction in their HADS Anxiety scores that the late group did not. Due to the very small numbers in this study this finding requires replication with a much larger sample.

It is important in this type of work to look at the clinical implications for participants. The participants in the early group have shown a significant decrease in their levels of anxiety but does this reduce their anxiety to normal levels? There are still the same number of participants scoring seven or above on the HADS Anxiety Scale (72%). However, some participants' scores overall have reduced, bringing them closer to the cut off.

3.4 Multiple Regression Analysis

From the above results, variables that showed some association at the 0.05 level of significance or below with participants' levels of anxiety or depression were selected for inclusion in multiple regression analysis. It was hoped that in doing so the variables that contribute to carers' psychological distress would be highlighted as well as providing some idea of their relative contribution. The following variables were selected for use in the multiple regression analyses, variables with the most statistically significant associations being entered first:

Patient Factors:

- Number of months post injury (MTHSPOST) (entered only in the analysis with depression scores)
- Objective burden (SYMPTOM 1) (entered into the analysis with anxiety and depression scores)

Carer Factors

Social Support:

- Actual practical support (APR1) and the discrepancy between actual and ideal practical support (DPR 1)(entered into the analysis with both depression and anxiety scores)
- The discrepancy between actual and ideal emotional support (DEM1)(entered into the analysis with depression)

Coping Strategies

- Focussing on and venting emotions (SFOCUS 1))(entered into the analysis with anxiety scores)
- Behavioural Disengagement (SBEHDIS 1))(entered into the analysis with depression scores)

Table 49 shows the results of a multiple regression analysis, with HADS Anxiety Scores as the dependent variable. (As this test is rather conservative, significance is reported at the $p<0.1$ level.)

Table 49: Multiple Regression Table for Variables Correlated With Participants Anxiety Scores

Dependent Variable	Variables in the Equation	Multiple R	Adjusted R Squ.	Final Equation Beta	t	Sig.
HADS Anxiety At Time 2	Step 1 – SFOCUS1	.534	.254	.361	2.40	<0.05
	Step 2 – SYMPTOM 1	.625	.335	.106	.65	NS
	Step 3 – APR1	.696	.411	-.036	-.19	NS
	Step 4 – DPR1	.771	.514	.500	2.34	<0.05

The results of the multiple regression carried out with those variables shown to be correlated with participants levels of anxiety (see Table 49) suggest that the following time one variables are predictive of anxiety at time two:

- discrepancy between actual and ideal practical support (DPR1).
- the use of focussing on and venting emotions as a coping strategy (SFOCUS1).

A change of one standard deviation on the discrepancy between actual and ideal practical support variable would produce a change of 0.50 standard deviations on anxiety. A change of one standard deviation in the variable SFOCUS1 (focussing on and venting emotions) would produce a change of 0.36 standard deviations.

Table 50 shows a similar multiple regression analysis with HADS Depression scores at time two as the dependent variable.

Table 50: Multiple Regression Table for Variables Correlated with Participants Depression Scores

Dependent Variable	Variables in the Equation	Multiple R	Adjusted R Squ.	Final Equation Beta	t	Sig.
	Step 1 – SYMPTOM1	.710	.483	.470	2.50	<0.025
HADS	Step 2 – MTHSPOST	.725	.483	.048	0.26	NS
Depression	Step 3 – DPR1	.773	.541	.044	0.17	NS
at Time 2	Step 4 – SBEHDIS1	.789	.547	.207	1.23	NS
	Step 5 – DEM1	.800	.545	.200	0.89	NS
	Step 6 – APR1	.806	.533	-.138	0.71	NS

Table 50 shows the results of a multiple regression analysis that identifies the following variable as predictive of participants' depression scores at time two:

- objective burden (SYMPTOM1).

A change of one standard deviation in the Symptom variable would lead to a change of 0.47 standard deviations on depression. The contribution of the other variables is relatively minor.

Summary of Multiple Regression Analyses

The discrepancy between actual and ideal practical support seems to be the more important predictor of participant anxiety at time two, and focussing on and venting emotions as a coping strategy is also a significant predictor.

Participants scores on the Symptom Checklist (their objective burden scores) are the most predictive of depression at time two.

3.5 Other Findings

Participants were asked to complete a questionnaire about the booklet they had received (see Appendix 3). The questionnaire asked participants about the readability, interest and style of the booklet as well as asking when the participant thought that the booklet would have been most useful and asking for any comments on information that should be included or excluded.

Only one of the twenty-seven respondents said that they had not read the entire booklet. Twenty-three said that the booklet was easy to read while four said it was reasonably easy. Twenty-two respondents said that it was easy to follow and the remaining five said that it was reasonably easy to follow. Twenty-two said that the booklet was very interesting and five said that it was reasonably interesting. Twenty of the twenty-six participants said that they found the booklet very helpful, six said that it was reasonably helpful and one person said that it was not at all helpful (although she said that she would have found it more helpful if she had received it earlier.)

The majority of participants said that they found the section "About Head Injury" the most useful section. Only a small number said that they found the information on helping themselves particularly helpful.

Figure 3 shows participants' responses to the question of when they felt it would have been most useful to receive the booklet.

Figure 4: Participants' Responses When Asked When the Information Booklet Would Have Been Most Useful

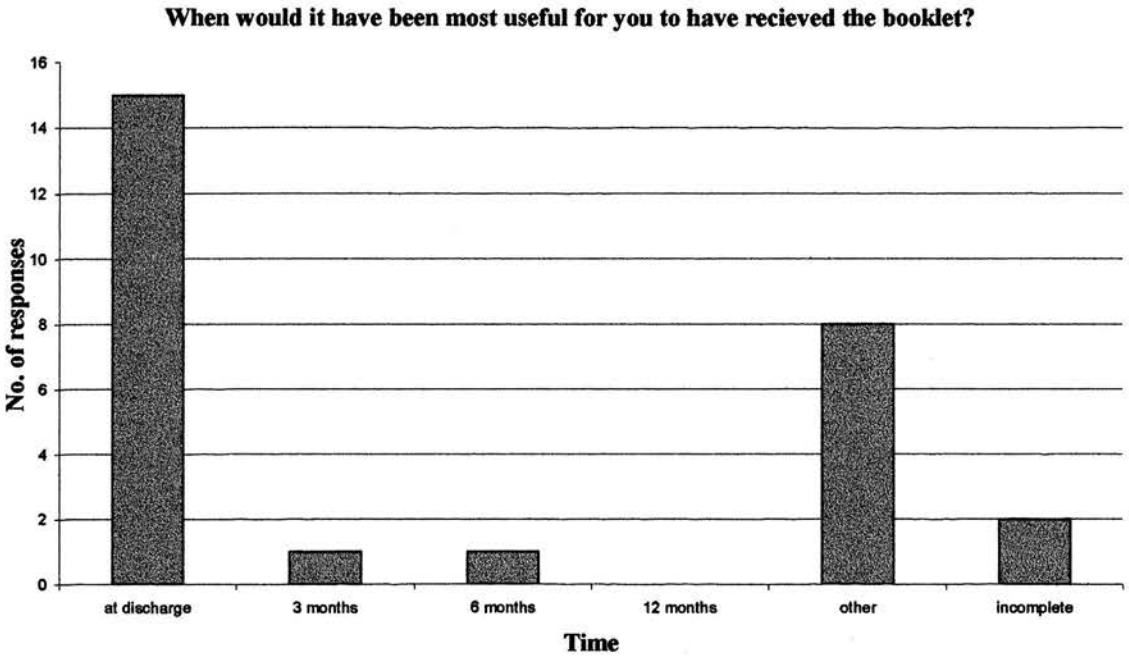

Figure 4 shows that the majority of respondents would have preferred to receive the booklet at the time that their relative was discharged from hospital. Those who gave an alternative response all said that the information booklet would have been most useful to them when their relative was still in hospital.

When asked if they had implemented any of the advice given, fifteen participants said that they had, ten said that they had not and two people failed to complete this question.

3.6 Summary of Results

General

Severity of injury as measured by GCS was not significantly correlated with levels of anxiety or depression for participants in this study. Number of months post injury was not significantly correlated with anxiety but was significantly correlated with depression. However this result may be due to the small numbers in this study and also the range of number of months.

Objective Burden, i.e. the physical, behavioural and emotional changes that occur following head injury, was significantly correlated with levels of anxiety and depression in carers.

Social Support

Anxiety was negatively correlated with levels of actual practical support when both groups were analysed together. The discrepancy between actual and ideal practical support was positively correlated. Depression and the discrepancy between actual and ideal emotional support were also positively correlated when both groups were analysed together. Actual practical support was negatively correlated with levels of **anxiety** in the late group (>12 months post injury) (i.e. the lower the practical support score, the higher the anxiety). The discrepancy between actual and ideal practical support was also correlated with **anxiety** in the late group. Actual practical support and the discrepancy between actual and ideal practical support were both significantly correlated with levels of **depression** in the late group, as was the discrepancy between actual and ideal emotional support.

Locus of Control

No significant correlations were found with anxiety or depression levels and Locus of Control orientation.

Coping Strategies

Participants did alter their responses between general and specific coping. In the early group the strategies that altered significantly were active coping, seeking

emotional support, the suppression of competing activities and positive reinterpretation. In the late group, acceptance and positive reinterpretation were the two strategies that changed significantly.

For the late group, the specific strategy of focussing on and venting emotions was significantly correlated with anxiety and the specific strategy of behavioural disengagement was significantly correlated with depression. Anxiety and depression scores in the early group did not correlated significantly with any specific coping strategy.

Experimental Hypotheses

When all participants' scores were included, there was a significant difference between time one and time two for GHQ scores but not for HADS Anxiety scores. When the early group was investigated separately (as the hypothesis suggested that it would be this group that would benefit most form the booklet) GHQ scores did not show a significant difference but HADS Anxiety scores did.

The late group showed no significant differences from time one to time two on either the GHQ or the HADS Anxiety scale.

Multiple regressions

Predictors of variance for HADS Anxiety scores at time two include, the discrepancy between actual and ideal practical support at time one, and focussing on and venting emotions as a specific coping strategy.

The best predictor of variance for HADS Depression scores at time two was objective burden.

Other findings

The majority of participants said that the booklet was easy to read, interesting and helpful. Fifteen of the twenty-seven participants said they would have found the booklet useful at discharge. Eight of the twenty-seven would have found the booklet useful while their relative was still in hospital and fifteen of the twenty-seven said that they had made use of the advice given.

CHAPTER 4 - DISCUSSION

4.0. DISCUSSION

As far back as 1972 Panting and Merry recommended that carers should be provided with information on the prognosis of head injury and on the emotional difficulties which frequently accompany it. In the years that followed researchers including Serio, Kreutzer and Gervasio (1995) and Sander, High, Hannay and Sherer (1997) repeated this recommendation. However, there appears to be little, if any, research looking at the benefits of providing information to carers and investigating questions such as when to give the information, who to give it to, and so on.

The principal aim of this study was to examine levels of anxiety and depression in carers of head injured individuals and to investigate the impact of providing carers with written information about head injury.

4.1.0 General Findings

Ethical consent was not initially granted for this study as the members of the committee felt that the information booklet contained information that was too distressing for carers. A small pilot study was therefore carried out to investigate carers' responses to the information contained in the booklet. Those carers involved in this pilot study reported that the booklet did not contain information that they felt was distressing and made no recommendations for information to be removed. This evidence, along with research that suggests that carers want the information whether or not it is distressing (Gentleman, Gilchrist and Neilson, 1996) was presented to the ethics committee and the study was approved.

Consistent with other studies of head injury and with the general literature on caregiving (see Introduction), the majority of primary caregivers in this sample were female (82%). Regarding relation to the patient with the injury, 61% (20) of the participants were partners, 36% (12) were parents and 3% (1) were siblings.

Unfortunately the numbers in each of these groups were too small to investigate any difference in, for example, psychological distress in males and females, their locus of

control, social support networks and coping strategies as well as their use of the information provided.

The participants involved in this study represented carers of individuals with a wide range of difficulties resulting from mild, moderate and severe head injuries. Patients' Glasgow Coma Scale scores (Teasdale and Jennett, 1974), which were used in this study as a measure of severity, ranged from 3 to 14, which represents mild, moderate, severe and very severe head injury (see Introduction, page 5). Many of the previous studies carried out in this area have only included relatives of individuals with severe head injuries (Novack, Bergquist, Bennett and Gouvier, 1991, Allen, Linn, Gutierrez and Willer, 1994, Livingston, Brooks and Bond, 1985) but Jacobs (1988) suggested that the majority of those who survive brain injury, whether mild, moderate or severe, will survive with impairments which interfere with daily living. Participants' scores on the Symptom Checklist, which measures carers' perception of the physical, behavioural and emotional changes in the head injured person (from a possible 0 to 77 score), ranged from 0 to 48 in the early group and 2 to 67 in the late group (see Table 10). These scores did not change significantly from time one to time two for either group (see Tables 12 and 13).

Interestingly, participants did not see themselves as "carers" and this initially caused some confusion. Partners of head injured individuals in particular said that they did not see themselves as carers but rather saw what they were doing simply as part of their "job" as a partner. This finding may have consequences for those who have developed services and supports for "carers" of head injured individuals. The people that these services are aimed at do not appear to realise that these services are set up for them. Certainly the majority of carers in this study were unaware that there were services set up for them as carers and not just for their head injured relative.

4.2.0 Hypotheses from the Literature

4.2.1 Hypothesis 1a and 1b

Levels of Anxiety and Levels of Depression will be Greater Than Those in the General Population.

Using the Hospital Anxiety and Depression Scale (HADS) as a measure of participants' anxiety and depression, the results suggest that the participants in this sample did exhibit high levels of anxiety and depression. Anxiety seems to be more prevalent, with seventy-two percent of the early group and sixty-four percent of the late group, scoring above the cut off of seven on the HADS. Thirty-six percent of the early group and thirty-six percent of the late group scored above the cut off for depression on the HADS.

These scores do suggest that the carers in this study were experiencing levels of anxiety and depression greater than that experienced in the general population, that is between three and six percent for anxiety (Weissmann and Merikangas, 1986) and approximately five percent for depression (Blackburn and Davidson, 1995).

Anxiety - The anxiety scores of this current sample seem to be much higher than those found in previous studies. Livingston (1987) found that one third of the relatives in his sample had a score of greater than seven on the Leeds Scale (equivalent to the HADS). Linn, Allen and Willer (1994) found that in their sample spouses of head injured individuals, fifty-five percent demonstrated anxiety symptoms. Direct comparison between these studies, however, is not possible as the samples of each differ. Livingston's sample include only those relatives caring for individuals with a severe injury and Linn et al.'s sample is made up of individuals more than one year post injury. Linn et al. also use a different scoring measure (SCL-90).

It may be the case that including mild and moderate cases as well as severe head injured individuals may have led to an increase in the overall levels of anxiety. The emotional and behavioural sequelae are perhaps much more unexpected for those participants whose relative has had a relatively minor injury.

However, it is possible to see that regardless of different scoring methods and differences between samples, a large number of carers of individuals with a head injury show elevated levels of anxiety.

Depression – There are conflicting reports on carers' levels of depression in the literature. Linn et al. (1994) report levels as high as seventy-three percent for the spouses of head injured individuals in their sample. In a study by Kreutzer et al. (1994) twenty-five percent of carers reported depression. Again due to methodological differences in the studies in this area it is not possible to directly compare these studies.

Although the participants in Linn et al. (1994) study report high levels of depression the authors suggest that this percentage show "mild" elevations in depression scores. The present study shows a similar finding. Overall, depression scores are lower than anxiety scores in this sample, and the depression scores reported are generally in the "mild" range (see Figure 1). It would appear that although carers do report increased levels of depressive symptomatology, they are unlikely to fall into the range of severe depression. These findings are therefore in keeping with Linn et al.'s (1994) findings. It would be of interest for future research to investigate which particular symptoms participants are reporting.

4.2.2 Hypotheses 2a and 2b

Levels of Anxiety or Depression will not be Significantly Related to Severity of Injury or Time Post Injury.

McKinlay and his colleagues have carried out much of the research in this area (for example, McKinlay et al. 1981). As a result, much of the literature reports findings in terms of objective and subjective burden rather than in terms of levels of anxiety and depression. The current study endeavoured to replicate McKinlay et al.'s (1981) results, which suggest that severity of injury and time post injury are not directly related to level of carer burden. However, instead of using McKinlay's seven-point scale (to measure subjective burden) the current study investigated whether anxiety and/or depression were correlated with severity of injury and time post injury.

Severity of injury - The results in this study suggest that participant's anxiety and depression scores were not significantly correlated with severity of injury (as measured by Glasgow Coma Scale scores). This finding is in line with previous literature which suggests that severity of injury is not of itself a good predictor of carer distress.

Time post injury – Brooks et al. (1986) followed up McKinlay's sample to five years post injury. They found that ninety percent of carers continued to report medium and high levels of stress (as measured by a seven-point "burden" scale). Again the current study used measures of anxiety and depression rather than a "burden" scale. Sixty four percent of participants in the late group (i.e. those participants caring for someone for more than one year) reported significant anxiety symptoms and thirty six percent reported significant depressive symptoms.

However, rather than looking at anxiety and depression levels at one point, the present study also looked at the correlation between anxiety and depression and the actual number of months post injury (ranging from 2 months to 98 months). Anxiety was not significantly related to number of months post injury. This finding, that anxiety levels do not appear to decrease over time, is in line with Brooks et al.'s (1986) findings.

Depression, however, was significantly correlated with number of months post injury in this sample ($r = 0.53$, $p<0.01$). This is an interesting finding, particularly as the general levels of depression in this sample were relatively low. The GHQ-28 also showed a significant relationship with number of months post injury ($r = 0.36$, $p<0.05$). A scatterplot of the raw data (see Figure 1) emphasises the increase in depression scores as time post injury increased, however, these results must be interpreted with caution as the greater numbers in the late group may account for this significant result.

It would be interesting, however, to look at the responses given by participants to investigate the types of responses endorsed.

The number of months post injury was entered into the regression analysis with depression (as measured by the HADS) as the dependent variable. However, the number of months post injury was not found to be a good predictor of depression at time two. Although there was a significant relationship between depression and time

post injury, when entered into the regression equation along with other variables (most significantly, objective burden), time post injury did not add any more to the explained variance. Taking into consideration carers objective burden scores it may be that the relationship between depression and number of months post injury is influenced by objective burden. The greater the number of months post injury the longer the carer has had to deal with the emotional and behaviour problems displayed by their head injured relative (objective burden) and this is likely to lead to depression in the carer.

4.2.3 Hypothesis 3a and 3b

Levels of Anxiety and Depression Will Be Significantly Related to Objective Burden

Following on from their argument that severity of injury and time post injury were not sufficient predictors of carer burden, McKinlay et al. (1981) suggest that a measure of objective burden would be a more useful predictor, i.e. the types of problems displayed by the head injured individual. The Symptom Checklist, developed by McKinlay and his colleagues (1987) is a measure of the physical, emotional and behavioural difficulties that the carer has noticed in their head injured relative over the preceding week. In the present study, both participants' anxiety and depression levels were significantly correlated with their scores on the Symptom Checklist. (Anxiety scores were correlated at the $p<0.05$ level and depression scores at the $p<0.001$ level.)

The Symptom Checklist scores were also entered into the regression analysis as an independent variable, where the dependent variables were anxiety and depression. Participants' scores on this measure contributed significantly to the variance when predicting their depression scores at time two, but not in predicting anxiety scores. Kreutzer et al. (1994c) report that their participants' scores on the Neurobehavioural Problem Checklist (a measure which appears similar to the Symptom Checklist used in this study) was the best predictor of every subscale on the Brief Symptom Inventory. Livingston et al. (1985) also reported that the number of patient problems (as reported by the caregivers) was the best predictor of burden scores. Although

these studies cannot be compared directly, it appears that the present study contributes additional evidence for these conclusions.

There has not been a great deal of research carried out using this version of the Symptom Checklist. The findings in this study would suggest that further work should be carried out using this instrument with carers of individuals with mild, moderate and severe injury and investigating further its use as a predictive measure of depression.

It is relatively simple to investigate and/or directly measure carers objective burden and as scores appear to be associated with both anxiety and depression it would seem important to put systems in place which may protect those carers most vulnerable to developing anxiety and/or depression.

4.2.4 Hypothesis 4a and 4b

Levels of Anxiety and Depression will be Lower for those Individuals who have High Levels of Social Support

Research in the area of head injury suggests that greater satisfaction with social support is related to lower levels of distress in carers (Sander et al., 1997). Using Power, Champion and Aris' (1988) Significant Others Scale in the present study, it was possible to investigate participants' emotional and practical support in terms of their "perceived" support and their "received" support.

Emotional Support - When all the participants in this sample population are taken together their scores suggest that there was no significant relationship between anxiety scores and actual emotional support (AEM) or the discrepancy between actual and ideal emotional support (DEM). For the depression scores, there was no significant relationship with actual emotional support but there was a significant relationship between depression and the discrepancy between actual and ideal emotional support ($r = 0.32$, $p<0.05$).

Practical Support - When all the participants in this sample population are taken together there was a significant relationship between anxiety scores and depression scores and actual practical support (APR) and the discrepancy between actual and ideal practical support (DPR).

When entered into a regression analysis, participants' discrepancy scores between actual and ideal practical support (DPR) were also shown to be predictive of participants' anxiety at time two ($t = 2.34$, $p<0.05$). However, DPR was not a significant predictor of depression scores.

Although it is necessary to interpret these results with some caution due to the small numbers in this sample, it appears that carers' anxiety can be predicted by the difference between their perception of the actual practical support they receive and the support they would like to receive. It may be possible then for services to add to the practical support carers are receiving. In order to do this however, it is important to investigate the type of support included under the heading of "practical support". The questions in the SOS which are included to make up the practical support score only ask whether the respondent can rely on a particular person for practical support, and whether or not they can spend time with this person socially. It is up to the respondent to decide what type of support "practical support" might refer to. Comments made by participants when completing this section suggested that some thought of practical support in terms of financial help while others thought of it as help with household chores. Further research on this interesting finding is necessary. Due to small numbers, it was not within the scope of this study to look at the differences between partners and parents or males and females in their social support and its relationship with anxiety and depression. However, further investigation of these variables is likely to offer greater insight into the effects of practical and emotional support on carers' anxiety and depression.

Kozloff (1987) suggests that, as time goes on, carers' social networks decrease. If it is accepted that social support provides a buffer to psychological distress then it is likely that, in this situation, as time passes, carers' levels of anxiety and depression may increase.

There was no relationship between anxiety scores and emotional or practical support or depression scores and emotional or practical support for the early group. However, for the late group (12 months or more post injury), there was a significant correlation between anxiety scores and actual practical support, between depression

scores and actual practical support and between depression scores and the discrepancy between actual and ideal practical support.

Although again these results must be interpreted with some caution, a relationship does appear to exist between practical support and anxiety and depression scores in carers who have been caring for a head injured relative for more than one year. This information may be helpful to advise on useful services within rehabilitation, particularly as this is the time when patients and their carers are beginning to receive less formal support from rehabilitation services. It may be possible to provide on-going practical support (if this concept were to be more formally defined) or to enable carers to maintain or establish their own informal support networks.

The measure used in the present study only asked carers about the support they received from family members and their best friend. It did not ask about outside support whether formal or informal. However, Leathem, Heath and Wolley (1996) suggest that in fact the carers in their study placed a high emphasis on family as a potential source of support and also showed a universal reluctance to ask for outside support.

Previous literature in this field suggests that carers report their practical support needs as

- having help from other members of the family in taking care of the head injured person and having a break from problems and responsibilities (Serio, Kreutzer and Gervasio, 1995)
- help with keeping the house, for example, shopping, cleaning and cooking (Kreutzer, Serio and Bergquist, 1994c).

In the present study participants' comments suggested that they felt that practical support referred to either help with household chores or financial support. This would be in line with previous literature. However, it is clear that "practical support" means different things to different people and research investigating this variable and its influence on carers' psychological health would be extremely valuable.

4.2.5 Hypotheses 5a and 5b

Levels of anxiety and depression will be lower for those individuals who have an internal locus of control orientation.

Krause and Stryker (1984) suggested that individuals with internal locus of control beliefs would cope more effectively with stress than individuals with an external locus of control orientation. This study investigated the relationship between participants' anxiety and depression and their locus of control orientation. The results show no significant relationship between either anxiety or depression scores and locus of control orientation.

Carver, Scheirer and Weintraub (1989) suggested that locus of control may also be related to coping style, however, in the present study there are no significant correlations between locus of control and any of the COPE subscales.

These findings may be due to the small numbers involved in this study or to the seeming irrelevance of this scale to the situation the respondent found him or herself in.

Given the findings in the more general literature regarding locus of control and its relationship with style of coping (Carver, Scheirer and Weintraub, 1989) and psychological distress (Krause and Stryker, 1984, and, Petrosky and Birkimer, 1991) it would seem necessary to investigate its role in this area further.

4.2.6 Hypotheses 6a and 6b

Levels of anxiety and depression will be lower for those individuals who adopt a more active, problem solving style of coping.

Before going on to discuss the results of the analysis carried out with regard to participants' styles of coping, it is perhaps relevant to note that participants had considerable difficulty completing this questionnaire. In particular, the differentiation between the general and the specific coping strategies seemed to pose the most difficulty. Also, as the COPE is not developed specifically for carers of a head injured population some of the questions seemed inappropriate. In light of these difficulties the results discussed below should be interpreted with care.

Carver, Scheier and Weintraub (1989), who developed the COPE, argue that it is useful in measuring both dispositional and situational coping strategies. In this study both were measured to develop a picture of how participants reported any change in their coping strategies to help them cope with the caring role. Significant changes for participants in the early group included, active coping, seeking emotional social support, the suppression of competing activities and positive reinterpretation. In the late group, participants significantly altered their responses only in positive reinterpretation and acceptance.

This is an interesting difference. Carers in the acute stages appear to be setting aside other activities to concentrate on their current situation, attempting to seek emotional support and to think positively about the situation and attempting to take direct action in relation to the "problem". Carers in the later stages, more than twelve months post injury, still appear to be actively attempting to reinterpret the events in a positive light but generally seem to identify in themselves a more accepting coping strategy.

If the problem focussed emotion focussed distinction were to be used it would appear that the early group are using both strategies, whereas the late group appear to be attempting only to alter their perception of the situation, an emotion focussed strategy (Oddy, 1995; Compas, Worsham and Sydney, 1997, Singer, 1984; Lazarus, 1993).

Do specific strategies correlate with anxiety and/or depression?

There are no significant correlations between anxiety or depression and the fifteen COPE subscales for the early group. For the late group, however, the specific coping strategy of focussing on and venting emotions was significantly correlated with anxiety and behavioural disengagement as a coping strategy was correlatetd with depression. Other important associations may have been excluded, as they did not reach the statistical level set for this analysis. However, these may come to the fore if a larger sample size were used.

Focussing on and venting emotions - Although there was not a significant difference between participants' general use of focussing on and venting emotions as a coping strategy and their specific use, there did appear to be a change in their responses which may account for the significant relationship. Participants appear to become clearer in their use of this coping strategy. This may be because the

questions which make up this subscale are fairly concrete, for example, as the situational responses are tapping strategies that are currently in use, respondents could be quite definite about stating whether or not they let their feelings out.

When entered into a regression analysis, this coping strategy was also a significant predictor of participants' anxiety ($t = 2.40$, $p<0.05$). Although this was not the most important variable in the regression analysis, explaining 25% of the variance, it is still of interest. The results suggest that as the use of this strategy for coping increases so will the carers level of anxiety. It would therefore be necessary for rehabilitation services and services in contact with head injured individuals and their carers following discharge, to be aware of the detrimental effects of this style of coping. It may be that advice could be given or alternative strategies taught to enable carers who would be likely to use this type of coping strategy to implement more helpful strategies.

Behavioural Disengagement – Participants' responses to the questions that make up the behavioural disengagement subscale appear to show a floor effect. Most of the respondents report that they rarely give up trying to reach their goals and the majority of scores are between four and six (four being the lowest score possible). Although the results appear somewhat similar when participants are asked how they cope specifically with their current situation, there is some variance in response. This slight variance may account for the significant result. However, this result does appear to make intuitive sense. Participants in the late group seem to be experiencing slightly higher levels of depression and behavioural disengagement may be recognised as a symptom of depression, where the sufferer gives up trying to achieve his or her goals. However, it may be argued that this strategy is protective. Lazarus (1993) argued that in certain circumstances, where nothing can be done to improve the situation, rational problem solving efforts can be counterproductive and may result in further distress. In this situation he suggests that emotion focussed strategies may be the best choice.

When entered into the regression analysis along with other variables, particularly objective burden, which accounts for 48% of the variance, behavioural disengagement was not predictive of depression scores at time two.

4.3.0 Experimental Hypotheses

4.3.1 Hypothesis 7

Levels of anxiety will be reduced by the provision of information

Ellis, Hopkin, Leitch and Crofton (1979) reported the helpful effects of giving supplementary information to patients on discharge from a respiratory unit. Benefits included improved understanding and recall of information regarding diagnosis, prognosis, medication and follow up arrangements. Brumfitt, Atkinson and Greated (1994) concluded from their study that carers of individuals with communication difficulties found written information preferable to verbal information alone. Toner (1987), in a study with carers of dementia sufferers, reported a reduction in levels of carer distress following the provision of an information booklet. He argued that, as uncertainty is recognised as a major source of stress, an intervention aimed at reducing that uncertainty would in turn reduce levels of stress.

The current study found that, when participants from both groups were included, there was a significant reduction ($t = 1.96$, $p<0.05$) in overall levels of distress, as measured by the General Health Questionnaire-28, from time one to time two. This is, however, only the case when the GHQ-28 is scored using the Likert scale. When the GHQ method of scoring is used the differences between the means does not reach significance. However, there does appear to be a trend towards significance. Participants did appear to be altering their responses on the GHQ-28 and were reporting "rather more" difficulty or feeling "rather less" able to carry out tasks at time two, rather than "much more" difficulty or feeling "much less" able to carry out tasks as was the case at time one.

There was not a similar reduction, however, in scores on the HADS Anxiety scale.

It would seem then that the GHQ-28 is measuring some change in participants' responses that the HADS Anxiety is not. It may be that this instrument is more sensitive to the types of symptoms that the carers in this group were experiencing.

4.3.2 Hypothesis 8

The Reduction in Levels of Anxiety will be Greater when Time Post Injury is Less

Novack, Bergquist, Bennett and Gouvier's (1991), in their study of primary caregivers of head injured individuals, found that, "uncertainty about the future was a major component of family member anxiety." Toner (1987) also suggested that uncertainty appeared to be a potential source of stress for carers of dementia sufferers. Novack, Berquist, Bennett and Gouvier (1991) reported that anxiety in their participants diminished between the admission and discharge of the head injured person into rehabilitation. They go on to suggest that this may be due to an increased understanding of recovery from head injury.

If written information, aimed at reducing uncertainty, were available, it would seem likely that those who are in the acute stages post injury would benefit most from it.

In the present study, there was a noticeable decrease in the GHQ scores from time one to time two for the early group, however, this trend was not significant at the $p<0.05$ level. HADS Anxiety scores however did show a significant reduction from time one to time two ($t = 2.10$, $p<0.025$). The late group did not show a significant reduction in GHQ scores or in HADS Anxiety scores. It is therefore possible to say that there is a greater decrease in anxiety for the early group than for the late group but it is not possible to conclude causality.

These results may be explained by, an improvement in the head injured individual over the time period, the passage of time alone, the information provided or another variable. It is possible to discard the possibility of improvement in the patient, as there was no significant difference between scores at time one and time two on the Symptom Checklist, allowing the conclusion that there was no significant improvement in the patient over the time period of this study. Sander, High, Hannay and Sherer (1997) found that carers in their study showed a reduction in distress levels as measured by the GHQ-60 when assessed from 0 to 18 months post injury. However, they acknowledged that this finding was inconsistent with previous research and suggested that the result may be due to the fact that all their participants were also involved in inpatient or out patient rehabilitation. The majority of research

in this area consistently suggests that there is little reduction in carers' levels of distress over time (see above for fuller discussion). In light of this, although time as a variable cannot be ruled out, other variables can also be considered.

Clinically, the reduction in participants' anxiety was only minimal and their scores on the whole did not move from above to below the cut off point for clinically significant anxiety.

It would appear, however, from the results of this study and from the comments of those participants involved that, in spite of this, the information booklet provided was of greater benefit to those carers who had only begun to take on the caring role.

4.4.0 Usefulness of Booklet

Responses to the questionnaire designed to gauge participants' feeling regarding the booklet were, in the main, favourable. Only one participant reported that she did not find the booklet helpful but she said that had she received it earlier (she was 5 years post injury) she would not have responded in this way.

The majority of respondents said that they would have preferred to receive the information either prior to or at the time when their relative was to be discharged from hospital. It would certainly seem that from anecdotal comments, both written and spoken, that the carers involved in this study would have valued this type of information a great deal earlier than it was available to them, for example, "I only wish I had had the booklet from the start. It has helped me a great deal".

4.5.0 Summary of Main Findings

The main findings of this study would seem to be the progress made in identifying predictors of carers' anxiety and depression, i.e. objective burden, the perception of the availability of practical support and coping by focusing on and venting emotions.

The results also suggest that written information may be of benefit to carers of head injured individuals in the early stages post injury. This information may help alleviate some of the anxiety experienced due to the uncertainty of the situation and although this finding is far from conclusive, carers in this study overwhelmingly reported that this type of information was invaluable to them.

4.6.0 Methodological Issues

There are a number of methodological problems in this study, which mean that the results should be interpreted with care. One of the main problems was the lack of a control group. It would have been particularly useful to have a group of carers who were caring for a head injured individual three to nine months post injury who did not receive the information booklet. In this way it would have been possible to compare levels of anxiety and depression over time. However, it was extremely difficult, given the restricted time period, to recruit sufficient numbers to the early group for the study so in this case a control group was not used.

Power calculations suggested a minimum of thirty participants in both the early group and the late group. This number of participants was not available in the limited time period. The small numbers of participants in each group led to limitations in the analysis of the data collected. This population is currently much researched and this led to increased competition for participants.

A further problem with the sample used in this study was that there was no account taken of previous rehabilitation or psychological input for either the patient or the participant involved. Participants were also not asked about any current medication. Rehabilitation or any other formal support from, for example, organisations set up to help and advise head injured individuals and their families or from psychology or psychiatry services is likely to have a large impact on psychological distress, the main focus of this study. However, in this area, these services have also received little attention, and little is known about their effects.

Participants were asked if they felt that any part of the booklet they received should be removed or if there was any information missing that they felt should be included. Only two people responded to these questions with any comment, the remainder answered no to both. One participant who's husband sustained a head injury a number of years ago suggested that information regarding intimate relationships and how they may change following head injury would be useful. Another respondent suggested that it might be useful to have case examples to highlight various behaviour problems.

However, as the majority of people did not feel that any changes were required, the content of the information booklet will remain unchanged.

4.7.0 Future Research

This study has highlighted many avenues for future research in this area. The findings in this study should be replicated taking into account and improving on the methodology. A control group should certainly be recruited to allow for direct comparisons to be made regarding the provision of the information booklet. Any replication should also include larger numbers.

It would appear that the majority of carers in this study would have preferred to receive the information provided at a much earlier time. Future research would certainly be required to investigate carers' anxiety and depression in the acute stages following head injury and the provision of information at discharge.

As the results of this study have shown some decrease in carers anxiety levels it may be beneficial to offer a fixed number of anxiety management sessions for those carers thought to be most vulnerable to clinically significant levels of anxiety. Singer et al. (1996) have offered this type of input to parents of children who have suffered head injury, with positive results, but further research is required.

Further investigations are also necessary in the area of carer characteristics, i.e. gender and relationship to the injured person. The present study suggests that practical support is a particularly useful variable when predicting participants' anxiety and depression. The small numbers involved here do not allow for investigation of the differences related to this variable when, for example, the injured person is the partner or the child of the carer.

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APPENDIX 1 – Pilot Study Questionnaire

CARER INFORMATION BOOKLET

The following questions relate to the information booklet you have received. They are designed to find out how easy it is to understand and how useful you think it might be for other carers of head injured individuals.

Please answer the following questions as fully as possible.

1. Is the booklet easy to read? *(Delete as appropriate)* **YES/NO**
2. Is the way the information is presented easy to follow? *(Delete as appropriate)* **YES/NO**
3. Is there any information you would have found upsetting and think should be removed? *(Please indicate the page numbers where that information is found.)*

   .....

   .....

4. Is there any information that you would like to see included? (*Please give details.)*

   .....

   .....

5. Would this information have been helpful to you? **YES/NO**
6. When would it have been useful for you to have received this information? *(Please tick box)*

At discharge	☐
3 months after discharge	☐
6 months after discharge	☐
12 months after discharge	☐
Other (Please give details)	☐

.....

Any other comments

.....

.....

[Thank-you very much for your time]

APPENDIX 2 – Questionnaires

COPE

We want to know how you cope in general and how you cope with the specific situation you find yourself in at the moment, as carer of someone with a head injury. Please go through the list with your stressor in mind. Please answer every item.

1 = I don't do this at all **3 = I do this a medium amount**

2 = I do this a little bit **4 = I do this a lot**

	Generally	**Specifically**
1. I try to grow as a person as a result of the experience.	1 2 3 4	1 2 3 4
2. I turn to personal or other substitute activities to take my mind off things.	1 2 3 4	1 2 3 4
3. I get upset and let my emotions out.	1 2 3 4	1 2 3 4
4. I try to get advice from someone about what to do.	1 2 3 4	1 2 3 4
5. I concentrate my efforts on doing something about it.	1 2 3 4	1 2 3 4
6. I say to myself "this isn't real".	1 2 3 4	1 2 3 4
7. I put my trust in God.	1 2 3 4	1 2 3 4
8. I laugh about the situation	1 2 3 4	1 2 3 4
9. I admit to myself that I can't deal with it, and quit trying	1 2 3 4	1 2 3 4
10. I restrain myself from doing anything too quickly.	1 2 3 4	1 2 3 4
11. I discuss my feelings with someone.	1 2 3 4	1 2 3 4
12.I use alcohol or drugs to make me feel better.	1 2 3 4	1 2 3 4
13. I get used to the idea that it happened	1 2 3 4	1 2 3 4
14. I talk to someone to find out more about the situation	1 2 3 4	1 2 3 4
15. I keep myself from getting distracted by other thoughts or activities	1 2 3 4	1 2 3 4

(Please turn over

Continue to answer each item with these response choices:

1 = I don't do this at all 3 = I do this a medium amount

2 = I do this a little bit 4 = I do this a lot

	Generally	**Specifically**
16. I daydream about things other than this.	1 2 3 4	1 2 3 4
17. I get upset and am really aware of this.	1 2 3 4	1 2 3 4
18. I seek God's help.	1 2 3 4	1 2 3 4
19. I make a plan of action	1 2 3 4	1 2 3 4
20. I make jokes about it.	1 2 3 4	1 2 3 4
21. I accept this has happened and that it can't be changed	1 2 3 4	1 2 3 4
22. I hold off doing anything about it until the situation permits.	1 2 3 4	1 2 3 4
23. I try to get emotional support from friend or relatives.	1 2 3 4	1 2 3 4
24. I just give up trying to reach my goal.	1 2 3 4	1 2 3 4
25. I take additional action to get rid of the problem.	1 2 3 4	1 2 3 4
26. I try to lose myself for a while by drinking alcohol or taking drugs	1 2 3 4	1 2 3 4
27. I refuse to believe that this is happening.	1 2 3 4	1 2 3 4
28. I let my feelings out.	1 2 3 4	1 2 3 4
29. I try to see it in a different light, to make it seem more positive.	1 2 3 4	1 2 3 4
30. I talk to someone who could do something concrete about the problem	1 2 3 4	1 2 3 4
31. I sleep more than usual.	1 2 3 4	1 2 3 4
32. I try to come up with a strategy about what to do.	1 2 3 4	1 2 3 4
33. I focus on dealing with this problem and if necessary let other things slide a little	1 2 3 4	1 2 3 4
34. I get sympathy and understanding from someone	1 2 3 4	1 2 3 4

Continue to answer each item with these response choices:

1 = I don't do this at all **3 = I do this a medium amount**

2 = I do this a little bit **4 = I do this a lot**

	Generally	**Specifically**
35. I drink alcohol or take drugs in order to think about it less.	1 2 3 4	1 2 3 4
36. I kid around about it.	1 2 3 4	1 2 3 4
37. I give up the attempt to get what I want	1 2 3 4	1 2 3 4
38. I look for something good in what is happening.	1 2 3 4	1 2 3 4
39. I think about how I might best handle the problem.	1 2 3 4	1 2 3 4
40. I pretend that it doesn't really happen	1 2 3 4	1 2 3 4
41. I make sure not to make matters worse by acting too soon.	1 2 3 4	1 2 3 4
42. I try hard to prevent other things from interfering with my efforts at dealing with this.	1 2 3 4	1 2 3 4
43. I go to the movies or watch TV to think less about it.	1 2 3 4	1 2 3 4
44. I accept the reality of the fact that it happened.	1 2 3 4	1 2 3 4
45. I ask people who have had similar experiences what they did.	1 2 3 4	1 2 3 4
46. I feel a lot of emotional distress and find myself expressing those feelings a lot.	1 2 3 4	1 2 3 4
47. I take direct action to get around the problem.	1 2 3 4	1 2 3 4
48. I try to find comfort in my religion	1 2 3 4	1 2 3 4
49. I force myself to wait for the right time to do something.	1 2 3 4	1 2 3 4
50. I make fun of the situation.	1 2 3 4	1 2 3 4
51. I reduce the amount of effort I'm putting into solving the problems.	1 2 3 4	1 2 3 4
52. I talk to someone about how I feel.	1 2 3 4	1 2 3 4

Continue to answer each item with these response choices:

1 = I don't do this at all **3 = I do this a medium amount**

2 = I do this a little bit **4 = I do this a lot**

	Generally	**Specifically**
53. I use alcohol or drugs to help me get through it.	1 2 3 4	1 2 3 4
54. I learn to live with it.	1 2 3 4	1 2 3 4
55. I put aside other activities in order to concentrate on this.	1 2 3 4	1 2 3 4
56. I think hard about what steps to take.	1 2 3 4	1 2 3 4
57. I act as though it hasn't even happened.	1 2 3 4	1 2 3 4
58. I do what has to be done one step at a time.	1 2 3 4	1 2 3 4
59. I learn something from the experience	1 2 3 4	1 2 3 4
60. I pray more than usual.	1 2 3 4	1 2 3 4

(Thank-you for completing the questionnaire.

Symptom Checklist

1. **Name**.....

2. **How are you related to the injured person?**

The person who is injured is my...(tick one)

Husband..... Wife.....Child.....Parent.....Brother..... Sister.....

If none of these, please state relationship.....

3. **Who is the main person(s) who looks after the person who is injured?**

.....

The questions that follow are about the injured person's health over the last few weeks, compared with his/her health before the injury.

DOES THE INJURED PERSON SUFFER FROM:

(For each question, circle the answer that applies)

4.**Poor vision**	no change	rather worse since injury	much worse since injury
5.**Poor hearing**	no change	rather worse since injury	much worse since injury
6.**Poor sense of taste**	no change	rather worse since injury	much worse since injury
7.**Poor sense of smell**	no change	rather worse since injury	much worse since injury
8.**Poor balance**	no change	rather worse since injury	much worse since injury

(For each question, circle the answer that applies)

9. **Dizzy spells**	no change	rather worse since injury	much worse since injury
10. **Headaches**	no change	rather worse since injury	much worse since injury
11. **Tiredness**	no change	rather worse since injury	much worse since injury
12. **Difficulty sleeping or disturbed sleep**	no change	rather worse since injury	much worse since injury
13. **Slowness**	no change	rather worse since injury	much worse since injury
14. **Tension or anxiety**	no change	rather worse since injury	much worse since injury
15. **Impatience**	no change	rather worse since injury	much worse since injury
16. **Finds noise distressing**	no change	rather worse since injury	much worse since injury
17. **Irritability**	no change	rather worse since injury	much worse since injury
18. **Outbursts of temper**	no change	rather worse since injury	much worse since injury

(For each question, circle the answer that applies)

19. **Outbursts of violence**	no change	rather worse since injury	much worse since injury
20. **Difficulty speaking (eg slurred speech, stammer)**	no change	rather worse since injury	much worse since injury
21. **Difficulty finding the right word**	no change	rather worse since injury	much worse since injury
22. **Difficulty understanding what words mean – NOT due to poor hearing**	no change	rather worse since injury	much worse since injury
23. **Poor concentration**	no change	rather worse since injury	much worse since injury
24. **Depression**	no change	rather worse since injury	much worse since injury
25. **Childishness**	no change	rather worse since injury	much worse since injury
26. **Sudden changes in mood**	no change	rather worse since injury	much worse since injury

(Please tick one answer to each question)

27. **Has the patient's personality changed as a result of the injury?**

No..... Yes.....

(Please tick one answer to each question)

28. **Has the patient become more passive, "not bothered" or has he/she less drive?**

No..... To some extent..... Very much so.....

29. **Is the patient's memory worse than before the injury?**

No different..... Rather worse..... Much worse.....

30. **If the patient's memory is worse, please answer these questions by ticking "yes" or "no".**

Does the patient forget the name of acquaintances?	Yes.....	No.....
Does the patient mislay things?	Yes.....	No.....
Does the patient fail to recognise faces or places?	Yes.....	No.....
Does the patient forget things you tell him/her?	Yes.....	No.....
Does the patient forget what day it is?	Yes.....	No.....
Does the patient get lost if out alone?	Yes.....	No.....

31. **Has the patient suffered any fits since discharge from hospital? (please tick one answer)**

None..... Occasional..... Regular.....

32. **Does the patient need to take tablets to prevent fits?**

No..... Yes.....

33. **As a result of the injury, is the patient disabled to the extent that stick, crutches, wheelchair, etc.,are needed to get about BY HIMSELF (OR HERSELF)?**

Fully independent, that is, no aids and no difficulty getting about .....

Gets around without aids but with some difficulty .....

Needs stick/crutch ..... Confined to wheelchair, can move self in it .....

Confined to wheelchair, needs pushed ..... Confined to bed .....

34. **Has the patient's sex life changed since injury?**

Not adversely affected..... Adversely affected ..... Don't know.....

(Please tick one answer to each question)

35. **Is the patient independent in self care (washing, dressing, toiletting)?**

No change due to injury..... Needs more help..... Needs a lot of help.....

36. **Does the patient need supervision outdoors?**

No change due to injury..... Needs more help..... Needs a lot more help.....

37. **Does the patient need help indoors?**

No change due to injury..... Needs more help..... Needs a lot more help.....

38. **Is the patient attending any out-patient clinics?**

Yes..... No.....

If "yes", please specify.....

39. **What is the patient's <u>NORMAL</u> line of employment?**

Please state.....

40. **Just before the injury, what was the patient's work status?**

Working full time..... Working part time..... Housewife..... Student.....

Retired..... Unemployed..... Unfit for work.....

41. **Please describe briefly the patient's PRESENT occupation (if any).**

Please state.....

42. **At the present time, what is the patient's work status?**

Working full time..... Working part time..... Housewife..... Student.....

Retired..... Unemployed..... Unfit for work.....

43. **Do you think the patient's future employment prospects have been affected by the injury?**

Not affected..... Affected to some extent..... Very much worse.....

(Please tick one answer for each question)

44. **Has the patient's leisure and social life been changed since injury?**

Little or no change.... Rather worse since injury.... Much worse since injury....

45. **Who was to blame for the injury?**

Patient's own fault..... Another person(s) was to blame..... No known.....

Other; please describe.....

46. **Has there been/will there be an action for compensation?**

Yes..... No.....

47. **Is it settled?**

Yes..... No.....

48. **How much strain have you yourself been under as a result of the injury?**

Place a tick somewhere from 0 = no strain to 10 = severe strain:

0	1	2	3	4	5	6	7	8	9	10
No strain										Severe strain

(Thank-you very much for completing the questionnaire)

SIGNIFICANT OTHERS SCALE (A)

Name:.....

Date:..... **Record Number:**.....

Instructions

Listed below are various people who may be important in your life. For each person please circle a number from 1 to 7 to show how well he or she provides the type of help that is listed.

The second part of each question asks you to rate how you would like things to be if they were exactly as you hoped for. As before, please put a circle around one number between 1 and 7 to show what your rating is.

Please note: if there is no such person in your life, please leave that section blank and go on to the next section.

Section 1 – Spouse (Husband/Wife) or Partner

		Never			*Sometimes*			*Always*
1	a) Can you trust, talk to frankly and share your feelings with your spouse/partner?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
2	a) Can you lean on and turn to your spouse/partner in times of difficulty?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
3	a) Does he/she give you practical help?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
4	a) Can you spend time with him/her socially?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7

Section 2 – Mother

1	a) Can you trust, talk to frankly and share your feelings with your mother?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
2	a) Can you lean on and turn to your mother in times of difficulty?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
3	a) Does she give you practical help?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
4	a) Can you spend time with her socially?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7

Section 3 – Father

1	a) Can you trust, talk to frankly and share your feelings with your father?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
2	a) Can you lean on and turn to your father in times of difficulty?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
3	a) Does he give you practical help?	1	2	3	4	5	6	7
	b) What rating would your ideal be?	1	2	3	4	5	6	7
4	a) Can you spend time with him socially?	1	2	3	4	5	6	7
	b) What rating would your ideal be	1	2	3	4	5	6	7

PLEASE CIRCLE ONE NUMBER ONLY FOR EACH QUESTION

THE GENERAL HEALTH QUESTIONNAIRE

GHQ 28

David Goldberg

Please read this carefully.

We should like to know if you have had any medical complaints and how your health has been in general, *over the past few weeks*. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

Have you recently

A1 – been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much worse than usual
A2 – been feeling in need of a good tonic?	Not at all	No more than usual	Rather more than usual	Much more than usual
A3 – been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
A4 – felt that you are ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
A5 – been getting any pains in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A6 – been getting a feeling of tightness or pressure in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A7 – been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual
B1 – lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
B2 – had difficulty in staying asleep once you are off?	Not at all	No more than usual	Rather more than usual	Much more than usual
B3 – felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
B4 – been getting edgy and bad-tempered?	Not at all	No more than usual	Rather more than usual	Much more than usual
B5 – been getting scared or panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual
B6 – found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
B7 – been feeling nervous and strung-up all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual

HAD Scale

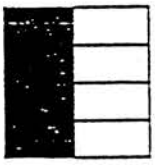
Name: Date:

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more.
This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.
Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

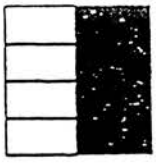
Tick only one box in each section

I feel tense or 'wound up':
- Most of the time .....
- A lot of the time .....
- Time to time, Occasionally .....
- Not at all .....

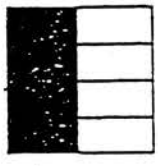
I still enjoy the things I used to enjoy:
- Definitely as much .....
- Not quite so much .....
- Only a little .....
- Hardly at all .....



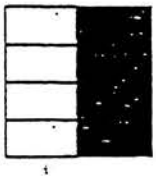
I get a sort of frightened feeling as if something awful is about to happen:
- Very definitely and quite badly .....
- Yes, but not too badly .....
- A little, but it doesn't worry me .....
- Not at all .....



I can laugh and see the funny side of things:
- As much as I always could .....
- Not quite so much now .....
- Definitely not so much now .....
- Not at all .....

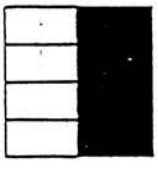


Worrying thoughts go through my mind:
- A great deal of the time .....
- A lot of the time .....
- From time to time but not too often ..
- Only occasionally .....

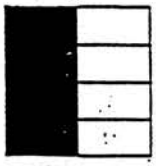


I feel cheerful:
- Not at all .....
- Not often .....
- Sometimes .....
- Most of the time .....

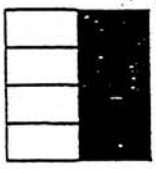
I can sit at ease and feel relaxed:
- Definitely .....
- Usually .....
- Not often .....
- Not at all .....



I feel as if I am slowed down:
- Nearly all the time .....
- Very often .....
- Sometimes .....
- Not at all .....

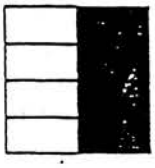


I get a sort of frightened feeling like 'butterflies' in the stomach:
- Not at all .....
- Occasionally .....
- Quite often .....
- Very often .....

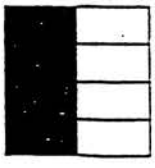


I have lost interest in my appearance:
- Definitely .....
- I don't take so much care as I should.....
- I may not take quite as much care .....
- I take just as much care as ever .....

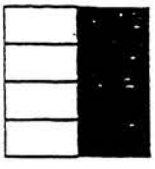
I feel restless as if I have to be on the move:
- Very much indeed .....
- Quite a lot .....
- Not very much .....
- Not at all .....



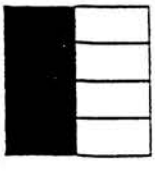
I look forward with enjoyment to things:
- As much as ever I did .....
- Rather less than I used to .....
- Definitely less than I used to .....
- Hardly at all .....



I get sudden feelings of panic:
- Very often indeed .....
- Quite often .....
- Not very often .....
- Not at all .....



I can enjoy a good book or radio or TV programme:
- Often .....
- Sometimes .....
- Not often .....
- Very seldom .....



Do not write below this line

Printed as a service to medicine by Upjohn

The Rotter I - E Scale (U.K. Version)

SOCIAL REACTION INVENTORY

This is a questionnaire to find out the way in which certain important events affect different people. This is a measure of personal belief: obviously there are no right or wrong answers. Each item consists of a pair of alternatives lettered a or b. Please select the one statement of each pair (and only one) which you more strongly believe to be the case as far as you're concerned, and put a ring around the appropriate letter, thus (a) or (b). Be sure to select the one you actually believe to be more true than the one you think you should choose or the one you would like to be true. Please put your age, sex and occupation in the spaces provided before completing it.

Please answer these items carefully but do not spend too much time on any one item. Be sure to find an answer for every choice. In some instances you may discover that you believe both statements or neither one. In such cases, be sure to select the one you more strongly believe to be the case as far as you're concerned. Also try to respond to each item independently when making your choice; do not be influenced by your previous choices.

REMEMBER - select that alternative which you personally believe to be more true

.....

AGE: ..... SEX: ..... OCCUPATION: .....

1. a. Children get into trouble because their parents punish them too much.
   b. The trouble with most children nowadays is that their parents are too easy with them.

2. a. Many of the unhappy things in people's lives are partly due to bad luck.
   b. People's misfortunes result from the mistakes they make.

3. a. One of the major reasons why we have wars is because people don't take enough interest in politics.
   b. There will always be wars, no matter how hard people try to prevent them.

4. a. In the long run people get the respect they deserve in this world.
   b. Unfortunately, an individual's worth often passes unrecognised no matter how hard he tried.

5. a. Without the right breaks one cannot be an effective leader.
   b. Capable people who fail to become leaders have not taken advantage of their opportunities.

6. a. No matter how hard you try some people just don't like you.
   b. People who can't get others to like them don't understand how to get along with others.

7. a. Heredity plays the major role in determine one's personality.
   b. It is one's experiences in life which determine what they're like.

8. a. I have often found that what is going to happen will happen.
   b. Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.

9. a. Becoming a success is a matter of hard work, luck has little or nothing to do with it.
   b. Getting a good job depends mainly on being in the right place at the right time.

/ P.T.O. ,,

APPENDIX 3 – Booklet Questionnaire

CARER INFORMATION BOOKLET

The following questions relate to the information booklet you have received. They are designed to find out how easy it is to understand and how useful you think it might be for other carers of head injured individuals.
Please answer the following questions as fully as possible.

1. How much of the booklet did you read? *(Please circle)*

   all of it **half of it** **none of it** **other**

2. Was the booklet easy to read? *(Please circle)*

   1 **2** **3** **4**
   not at all easy **very easy**

3. Was the way the information was presented easy to follow? *(Please circle)*

   1 **2** **3** **4**
   not at all easy **very easy**

4. Was the information presented interesting? *(Please circle)*

   1 **2** **3** **4**
   not at all interesting **very interesting**

5. Was the information helpful? *(Please circle)*

   1 **2** **3** **4**
   not at all helpful **very helpful**

6. Please rate the following sections of the booklet in order of usefulness.
   (With 1 as most useful and 4 as least useful)

   About head injury ☐
   Cognitive impairment ☐
   Emotional and behavioural change ☐
   Looking after yourself ☐

7. Is there any information you think would have been useful that was not included in the booklet? (*Please give details.)*

.....

.....

8. Is there any information that you think should be removed from the booklet? *(Please give details)*

.....

.....

9. When would it have been most useful for you to have received this information? *(Please tick box)*

At discharge	☐
3 months after discharge	☐
6 months after discharge	☐
12 months after discharge	☐
Other (Please give details)	☐

.....

10. Have you implemented any of the advice given? **YES / NO**

10b. If yes, please give details

.....

.....

.....

Any other comments

.....

.....

.....

.....

.....

.....

[Thank-you very much for your time]

APPENDIX 4 – Letters and Information Sheet

NB. All letters and Information Sheets were altered depending on the centre at which the participant was to be seen. The format for both centres was the same and only one set is presented here.

(LETTER TO PATIENT)

Dear

I am writing to let you know about a study that we are carrying out at Dundee Royal Infirmary to help us understand more about some of the difficulties experienced by relatives/partners when living with someone with a head injury.

As someone who has recently experienced a head injury I am writing to you to seek you consent for my colleague Katharine Morris to contact your relative/partner.

The study would only involve your relative/carer and you would not be required to take any further part in it. This letter is simply a request for your consent for your relative/partner to be contacted.

Participation in this study is entirely voluntary and you or your relative/partner are free to refuse to take part or to withdraw from the study at any time without having to give a reason and without this affecting your or your relative/partners' future medical care.

If you have any questions please contact Katharine Morris at the Clinical Psychology Department, Dundee Royal Infirmary (Tel. 01382 346679).

Thank you very much.

Yours Sincerely

Dr. June Gilchrist

Consultant Neuropsychologist

……

I do / do not give my consent for you to contact my relative/partner, ……., for the purposes of this study. *(Please delete as appropriate, inserting your relative/partner's name, and return slip in envelope provided.)*

(LETTER TO CARER)

Dear

I am inviting you to take part in a study that we are carrying out at Dundee Royal Infirmary to help us understand more about anxiety and depression in relatives/partners of individuals who have had a head injury. We are looking at the relationship between levels of anxiety and depression and the availability of information about head injury and ways of coping.

We are asking people like yourself, who are relatives/partners of someone with a head injury, to attend an appointment at DRI (or at home if this is more convenient) to meet with my colleague Katharine Morris. Your details were obtained from your relative's medical notes and they have given their consent for me to contact you. Involvement in the study would be for two sessions of approximately one hour each, four weeks apart. You would be asked to complete a number of questionnaires and, following this you would be sent an information booklet about head injury. I would hope to contact you one week after the booklet had been sent to ensure you received it and to answer any questions you may have. Three weeks after this you would be asked to complete the questionnaires again.

If you agree to participate in the study I am required to notify your General Practitioner of your involvement and the nature of the study but all the responses you give will be confidential.

Further details about the study are included in the information sheet I have enclosed for you to read. I have arranged an appointment for you, should you be willing to help us.

Please telephone Katharine on 01382 346679 if you are able to help us (you can leave a message on the answerphone if she is not there). Please also phone if you would like to take part but find that the suggested appointment is not convenient, or if you want more information. If you prefer, you can simply return the attached form in the reply-paid envelope.

Thank-you very much.

Yours Sincerely

Dr. June Gilchrist
Consultant Neuropsychologist

INFORMATION SHEET FOR PARTICIPANTS

As a relative/partner of someone with a head injury you have been chosen as a possible participant in a study, the aim of which is to increase our understanding of stress and coping. To help you to understand what the research is about I am providing the following information that I want to be sure you understand before you decide whether to participate. Please ask any questions you have about the information that follows, and I will do my best to explain and to provide any further information you require.

Participating in the study would involve you completing a number of questionnaires about any current difficulties you have and your ways of coping. This will take approximately 1 hour. I would hope to offer you an appointment at Dundee Royal Infirmary or arrange to come to your home to go through these questionnaires with you. After you have completed the questionnaires you will be given an information booklet about head injury and some of its psychological effects. One week after your appointment I will contact you by telephone to answer any questions you may have. Three weeks after this you would be asked to complete the same questionnaires again. All the responses you give will be confidential. I am, however, required to advise your General Practitioner if your responses indicate that you seem significantly distressed by your current situation.

Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without having to give a reason and without this affecting your or your relatives' future medical care.

If you have any questions, more information can be obtained from Katharine Morris at the Clinical Psychology Department, Dundee Royal Infirmary (Tel. 01382 346679).

REPLY FORM

Name .....

Address .....

.....

.....

Telephone Number .....

Appointment

Date .....

Time .....

Please delete as applicable:

- I will be able to attend Dundee Royal Infirmary at the date and time indicated above.

- I will not be able to attend Dundee Royal Infirmary on the day and time indicated, but would like to make another appointment. The most convenient times for me are:

  .....

- I am not interested in taking part in the study outlined in your letter.

Further information is available from

Katharine Morris
Clinical Psychology Department
Dundee Royal Infirmary
Tel. 01382 346679

Please return in the reply-paid envelope.

(LETTER TO GP)

Dear

As part of a research study looking at psychological distress in carers, we have contacted individuals who are currently caring for someone with a head injury. If consent is given the person is invited to attend an appointment at Dundee Royal Infirmary to meet with my colleague Katharine Morris (or arrange an appointment at their home if that were more convenient). I am writing to let you know that one of your patients,..... ,has been or is currently involved in this study. The study consists of two sessions of approximately one hour each, four weeks apart. During these sessions the participant is asked to complete a number of questionnaires about any current difficulties they have and their ways of coping. After completing the questionnaires the participant is given a booklet about head injury, some of its psychological effects and suggestions for ways of to help them cope with their current situation. The participant is then contacted one week after their initial appointment to answer any questions they may have regarding the booklet. Three weeks after this the participant is asked to complete the questionnaires again.
We will contact you again if your patient's responses indicate any clinically significant distress or other problems.

Please contact Katharine Morris or myself on 01382 346679 if you would like any further information regarding this study.
Thank-you very much
Yours Sincerely

Dr. June Gilchrist
Consultant Neuropsychologist

(FINAL LETTER TO GP)

Dear

As you are aware.....D.O.B..... has been involved in a study investigating psychological distress in carers of head injured individuals.

Some of the measures taken indicate that ..... is reporting severe anxiety symptoms.

Although ..... has not indicated that she would like to do anything further about this, ethical guidelines require me to inform you of the situation.

Yours Sincerely

Katharine Morris
Clinical Psychologist
in training with Dr. J. Gilchrist
Consultant Clinical Neuropsychologist

Consent Form

Title:

Psychological Distress In Carers of Head Injured Individuals: Ways of Coping, Locus of Control and Effects of Giving Written Information.

Investigator:

Katharine Morris
Department of Clinical Psychology
Dundee Royal Infirmary
Dundee
Tel. 01382 346679

Further Information is Available from:

Dr. John Bogue
Clinical Psychologist
Royal Edinburgh Hospital
Edinburgh
Tel. 0131 5376279

- I agree to participate in this study.
- I have read this consent form and have had the opportunity to ask questions about the study.
- I agree for notice to be sent to my General Practitioner about my participation in this study.
- I agree to the provision of any clinically significant information to my General Practitioner.
- I understand that I am under no obligation to take part in this study and that a decision not to participate will not alter the treatment that I would normally receive.
- I understand that I have the right to withdraw from the study at any stage and that to do so will not affect my treatment.

Consent Form continued:

Signature of Participant:

.....

Name of Participant:

Signature of Investigator:

.....

Date:.....

Three copies to be made:

Top copy to be retained by Investigator

Second copy to be retained by the participant

Third copy to be sent to the participant's General Practitioner.

HEAD INJURY

Putting It All Together

Katharine Morris

Contents

Section 3 **Emotional and Behavioural Change**

Section 4 **Looking After Yourself**

SECTION 1 ABOUT HEAD INJURY

- What is a head injury?
- What happens in a head injury?
- Degrees of severity of injury

The brain does all our thinking, reasoning and planning. It stores memories and controls physical actions i.e. walking, talking, and so on. It also controls our feelings.

We often take its work for granted and only become more aware if an injury occurs.

Most families and head injured people want to know more about how the brain may be damaged and what effects this damage may have.

What is a head injury?

A head injury can be defined as "damage to living brain tissue that is initially caused by external mechanical forces". It can happen to anyone no matter who you are or what you do. Head injuries are most commonly caused by road traffic accidents, domestic and industrial accidents, sports and recreational injuries and assaults.

What happens in a head injury?

The head injury is usually not just one injury but a series of injuries. The initial injury occurs as a direct result of the accident and occurs at the time of injury. The secondary injury occurs 1 or 2 hours later and is due to a lack of oxygen to the brain and bruising and swelling in the brain.

Initial Injury

There are three sorts of first injury. These are closed head injury, penetrating injury and crushing injury.

Closed head injuries are the most common and are so named because there is no open wound. A closed head injury occurs when the head starts or stops moving suddenly, for example, by colliding with another object. As the head is accelerated, decelerated or rotated the brain is forced to follow the movements and damage occurs. The brain, which is made up of soft tissue, is damaged because the violent movement twists and tears the nerve fibres, veins and arteries that run through it. This type of injury causes widespread damage.

Also, because there is little space between the skull and the brain the violent movement will cause the brain to be hit against the skull causing further damage.

Penetrating injuries are comparatively rare and occur when the scalp and skull are cut through and the brain is exposed and damaged. This may occur as a result of a bullet or other sharp object entering the skull. This usually leads to damage in one small area and the rest of the brain is relatively undamaged in other areas. However, acceleration injuries can occur at the same time causing problems outlined above.

Crushing injuries are the least common type and occur when the head is caught and crushed between two objects. Often damage is not to the brain but to the base of the skull.

It is important to remember that often in accidents there is more than one injury. For example, in a car accident, the brain may be damaged when the collision occurs and then the person may be thrown from the car, hitting their head again causing further damage.

Secondary Injury

The second injury occurs in the first hour or so after the first injury. It happens as a result of a problem with the supply of oxygen to the brain. If the brain cells are starved of oxygen even for 2 or 3 minutes some will die. Oxygen supply may be interrupted because the windpipe is blocked, with blood or vomited food, or it may be as a result of a drop in blood pressure caused by bleeding elsewhere in the body.

Bruising, bleeding and swelling may also occur at this time.

Bruising and Swelling – The brain bruises and swells when it has been injured just as other parts of the body do. This is due to the tearing and bleeding of blood vessels and the leakage of body fluid in this area. Normally the brain fits inside the skull with only a little space to spare. When it swells the space is taken up and the pressure inside the skull – the intracranial pressure – rises and the brain is squeezed against the walls of the skull causing damage. This squeezing means that the blood, which is carrying oxygen to the brain, has difficulty circulating in the brain.

Bleeding – Sometimes veins or arteries are torn at the moment of injury and the blood escapes in one place to form a blood clot. The clot will squeeze the brain as described above, causing damage and will also increase intracranial pressure. This can be removed by an operation.

Degrees of Severity

Severity of injury varies enormously and there are a number of categories that are helpful in distinguishing severity of

injury. The length of time in coma and/or the period of posttraumatic amnesia define each category.

Mild Head Injury – This category accounts for more than 75% of all head injuries and there are 250 - 300 per 100,000 in the U.K. per year. A period of altered consciousness and a posttraumatic amnesia of less than one hour define it.

Moderate Head Injury – 18 per 100,000 in the U.K. per year fall into this category and it is defined as coma for 15minutes to 6 hours and a posttraumatic amnesia of up to 24 hours.

Severe Head Injury – 10 –15 per 100,000 in the U.K. per year fall into this category and it is defined as coma for 6 hours or more and a posttraumatic amnesia of 24 hours or more.

Summary

There is a series of injuries to take into account when talking about head injury.

- The "first injury" can be a closed, penetrating or crushing injury and occurs at the time of the accident.
- The "second injury" occurs an hour or so later and is as a result of an interruption of the flow of oxygen to the brain.

There is a wide range of problems following head injury including:

Physical e.g. clumsiness, unsteadiness and weakness
Cognitive e.g. memory, thinking and communication
Emotional e.g. anxiety, anger and depression
Behavioural e.g. irritability and disinhibition
Social e.g. making and keeping friends

Although the person may be well enough to return home there are still many problems to be faced and if you know about them in advance you will be better prepared to deal with them. This booklet will look at the cognitive, emotional and behavioural problems.

These problems are constantly changing and while progress does occur, all the problems do not improve at the same speed. Improvement is fastest early after injury but even months after the injury progress still occurs.

Not everyone has all the problems described below but anyone can have any group of them.

SECTION 2 COGNITIVE IMPAIRMENT

- What is cognitive impairment?
  - Memory
  - Attention and Concentration
  - Speed of Information Processing
  - Problem Solving
  - Language
- What can you do?
- Fatigue

What is cognitive impairment?

The term "cognitive" refers to our mental abilities, such as thought, concentration and memory. These skills are located in different parts of the brain and a head injury may damage some skills and not others. All those with moderate or severe head injuries are likely to experience some difficulties in this area particularly at the early stages of recovery and some problems may persist.

Memory Problems

Successfully remembering something requires three basic processes. First the item must be noticed or attended to, second it must be stored in memory and finally it must be retrieved.

There are different stages and parts in these processes that can be affected by head injury. It is not unusual for some parts to work and others not to and this makes it hard for carers and friends to understand that the person has a memory problem.

Post-traumatic amnesia is the loss of memory for events following the injury and may range from a few minutes to weeks, months or even years. Post-traumatic amnesia is often likened to sleep walking as the person can talk, walk around, and so on but is unable to remember this later.

Retrograde amnesia involves a loss of memory for events prior to the injury and may extend back for minutes, days, months or even years. Gradually the memories return but the person is unlikely to remember events immediately prior to their accident.

Short-term memory or "everyday memory" is the most common and probably the most difficult memory problem following head injury. The person may have difficulty remembering new information such as appointments and names and this can disrupt many aspects of their life.

What can you do?

One of the easiest strategies to help the head injured person remember is by encouraging him to take the load off his memory by "externalising" the memory i.e. by writing things down, keeping a diary or a calendar.

It is also helpful, when trying to improve memory, to repeat the information that is being given, to give it in small amounts or associate it with a picture.

Attention and Concentration

A head-injured person will find it difficult to keep his attention focused on one thing and will be easily distracted by other things happening around him. His attention span may also be very short. He will also be unable to divide his attention to concentrate on two things at once, for example, writing down a telephone message. This raises safety issues because, for example, he may leave the cooker on when answering the doorbell and then forget about the cooker.

What can you do?

If the person needs to concentrate on something it should be done in a quiet room, free from distraction and at a time of day, usually first thing, when he is fresh and alert.

Speed of Thinking

To react to new information it is necessary to take it in, process it and then act on it. Widespread damage to the brain

means that communication between the nerve cells is not as efficient, so reactions are slowed in individuals with a head injury. This means that they often feel left behind in conversations or are less able to follow the plot in a film. Physical reactions may also be slowed. The person can be unaware that he is slow.

What can you do?

One of the most useful things to remember is that the individual is not intentionally being obstructive by doing things slowly; he is unable to do things more quickly. It is therefore important to plan ahead and leave enough time for him to get ready, or to do a task.

It is also important not to give too much information at once, not only because of slowed reactions but also because of possible concentration difficulties.

Problem Solving

The group of skills involved in problem solving includes planning, organisation and creativity, and is often referred to as "executive function". This group of skills, based in the front

part of the brain, an area, as mentioned before, which is often damaged in head injury. A person with a head injury may have difficulty identifying problems, thinking of solutions and may be quite inflexible in their thinking. It is common for the head-injured person not to be aware of these difficulties. The inability to see their behaviour from another persons point of view can make a head-injured person seem self centred. Their difficulty with changing their own behaviour can often cause embarrassment to their carer.

What can you do?

As the head-injured person cannot easily assess their own behaviour, they cannot change their behaviour by themselves and they depend on others to help them. It is helpful to give direct, immediate feedback that does not sound like criticism. This is obviously very difficult to do and takes practice and patience. It may also be helpful to try to put routine or structure into the day so that things are made easier for them.

Language

Language skills are very complex and problems can occur in any of a number of different areas. A person with a head injury may have difficulty expressing himself or in understanding what is being said. People with expressive difficulties may have problems finding the words they want to say, perhaps giving the impression that they did not understand what was said. On the other hand, people with receptive problems may give the impression that they understand more than they actually do.

Other problems that may fall under the heading of language include constant talking and taking things literally.

What can you do?

Understanding difficulties -Try not to speak too quickly and use non-verbal communication, i.e. facial expression, gestures, etc.

Expressive difficulties – Allow the person time to put over what they are trying to tell you and encourage them to use non-verbal communication too.

Fatigue

All the problems described above do not happen in isolation from one another and they are also affected by other factors, especially fatigue.

Usually when we get up in the morning after a good nights sleep we feel refreshed and ready to go. We can work right through the day before beginning to get tired and we start to make mistakes. A person with a head injury will also feel fresh when he gets up in the morning but instead of being able to work through the day he will begin to get tired and make mistakes much more quickly, even after an hour or two. It seems that sleep has not given him as much energy as he expects. This is very difficult to understand and often when he starts to make mistakes in whatever he is doing the head injured person will feel that he must simply try harder. However, this only leads to a further deterioration in performance.

What can you do?

The first thing to remember is that when a person is fatigued he is unlikely to sit or lie down. He is much more likely to become restless, distractible, talkative or moody.

Monitoring the person's activities so that they alternate between activities that use a lot of energy and rest times is very important.

Summary

There are a number of problems that may become more obvious after the head-injured person returns home.

These include problems with memory, attention and concentration, speed of information processing, problem solving and language.

They are difficult to understand because they can't be seen and some specific skills remain. However there are things that you can do to help.

SECTION 3 EMOTIONAL AND BEHAVIOURAL CHANGE

- Influences on emotion and behaviour following head injury
- What changes occur?
  - Anger and Irritability
  - Emotional lability
  - Anxiety and Depression
  - Impulsivity and Disinhibition
  - Apathy
- What can you do?

Influences on emotion and behaviour following head injury

Emotional and behavioural changes seem to be inevitable following head injury as they are controlled by the front part of the brain – the frontal lobes – which are frequently damaged in head injuries. These changes are difficult to understand because they are unseen and people often report a sense that

the head-injured person is no longer the person they used to be.

Emotional and behavioural changes occur as a result of the brain damage itself and the interaction with the psychological reaction to the injury and it's consequences.

What changes occur?

It is important to remember that the head-injured person may not have all of the problems described below.

Anger and Irritability

The head-injured person may be impatient, intolerant and irritated and this may result in outbursts of verbal or physical aggression. Angry and irritable behaviour is often a direct result of damage to the part of the brain that controls regulation of emotion and frustration tolerance. These skills are located, as mentioned earlier, in the frontal lobes.

At first the person will have little control over his behaviour and may be abusive to anyone and everyone. As he relearns how to control his emotions you may find that his behaviour

with rehabilitation staff is good but when he is at home he still displays abusive behaviours. There is a simple explanation for this. When he is with you he feels relaxed, safe and loved. He does not feel this way with the staff. He therefore puts a great deal of energy into controlling his anger when out and is only able to relax when he returns home. You are, therefore, a real safety valve for him.

Stress and frustration can make these problems worse.

What can you do?

The most important thing that you can do is not to take the behaviour personally and try to treat each incident separately. Remember that it is a result of the brain damage. Help the rest of the family to deal with the situation in a consistent way. Life is easier to deal with if it is predictable so it may also be helpful to add some structure the day. Finally, make sure you have someone to talk to so that you can let off steam yourself.

Emotional Lability

This simply means that due to the brain damage the head-injured person is unable to discriminate when and how to express his emotions appropriately. The result is that he may react unpredictably to situations that would not have been difficult previously and may experience rapid and dramatic mood swings. The head-injured person's ability to control their emotions will fluctuate with fatigue.

What can you do?

As mentioned previously it is possible to relearn increasing emotional control. You can help by trying to point out, praise and discuss situations where the person was able to control their emotions and by modelling calm behaviour yourself.

Anxiety and Depression

Anxiety and depression are very common, normal reactions following head injury. Often anxiety is about recovery, the future and, after a period of dependency, being able to do things alone. Depression also comes at later stages of recovery when the head-injured person begins to realise the

full extent of their losses and change in their life. It is easy to see depression as a natural and realistic reaction to the situation but it is also a sign of progress. The head-injured person is gradually regaining some insight into his situation. This can help with motivation for rehabilitation and is seen as a major step on the way to adjustment and acceptance.

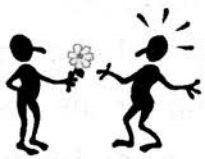
What can you do?

It is important to encourage independence and not try to do everything for the head-injured person. If he continues to depend on you his anxiety for going into new situations will remain high and his confidence will remain low.

If he seems depressed it may be helpful to divert his attention onto other things. It is tempting to remind him of how things were to emphasise his progress but this is not helpful and may make him more depressed. Remember not to take responsibility for his depression. It is not your fault.

Impulsivity and Disinhibition

This refers to the head-injured person's loss of ability to control their behaviour; for example, behaving in a certain way without weighing up the consequences, with the result that family and friends may be frustrated or embarrassed. This goes along with a lack of awareness about other people's reactions to one's behaviour. Again these behaviours are a direct result of the brain damage sustained.



What can you do?

The main thing that you can do is to remember that the problem is due to the brain injury. Give the person firm and direct feedback when he behaves inappropriately and try not to reinforce the behaviour. It may also be helpful to redirect the person's attention towards more appropriate behaviour.

Apathy

As a result of the damage to the brain the head-injured person may become passive and lacking in initiative. However, participation in activity takes planning and this takes a great deal of effort and can be seen as difficult and threatening.

What can you do?

It is sometimes helpful to say what you would like the person to do rather than asking if they would like to do it. Try also to break activities down into smaller steps and reward the person for their achievements.

Summary

A head injury leads to changes in emotion and behaviour. These are difficult to understand and difficult to cope with. However,

Remember that the behaviour is a direct result of the brain damage. Don't take it personally.

Try to respond consistently.

SECTION 4 – LOOKING AFTER YOURSELF

- What to expect
- Anxiety
- Grief and Depression
- Anger
- Tiredness
- What can you do to look after yourself?

What to expect

Looking after someone with a head injury is very stressful and the whole family has to learn to adjust to the effects of the injury. Some families will cope better than others will but all will have some difficulties. Research suggests that caregivers are likely to experience high levels of anxiety and depression. They may also feel angry, guilty, isolated and very tired.

Anxiety

Carers can often feel anxious or worried about the future asking themselves, "what progress will be made?", "what difficult behaviours will remain?", and so on. Anxiety is often focussed on the head injured persons ability to achieve the various goals set for him and so levels of anxiety fluctuate as different stages are reached.

Symptoms of anxiety include muscle tension, irritability, headaches, aches and pains, and so on.

Grief and Depression

Eventually the carer has to come to terms with the large number of changes in his or her life. These changes are often seen as losses, i.e. the loss of someone you knew, loss of a particular lifestyle, and so on. The carer needs to grieve for these losses because only then are they able to give up the past and start planning for the future. Sadness and grief are natural reactions and a crucial stage in acceptance of what has happened.

Anger

Again anger is a natural reaction in the circumstances and is often directed at the people closest to you. Anger is often a symptom of anxiety and is much less well controlled when a person is tired. Often people who are not carers don't really understand what the difficulties are and this too can be irritating for the carer.

Tiredness

Constantly caring for and worrying about a person is extremely tiring. Lack of sleep is common for carers who are anxious or depressed.

What can you do to look after yourself?

General

- Try to get enough sleep
- Make time to spend some time away from the person you are caring for to relax. Don't feel guilty about it.
- Eat regularly and properly to keep your energy levels up and to help you from feeling more tired.
- Talk to people about your worries and don't bottle them up, it helps.
- Accept help if it is offered. Be specific about what you would like the person to do for you. Sharing the care with other people.
- Keep up your own social contacts, don't stop seeing friends.

Specific

Anxiety

- remember to talk to others about your worries and don't keep them to yourself
- don't try to do everything for everybody

- learn some relaxation techniques

Depression

- allow yourself time to cry and to remember the past
- make the most of what the person you are caring for can do
- modify your goals and expectations
- practice saying the right things to yourself – things that make you feel good

Anger

- identify the triggers and try to change or avoid them
- let go of your anger through vigorous activity or to someone you trust
- accept that it is normal

Tiredness

- get as much sleep as possible and set up a bedtime routine

- If you are finding it hard to get off to sleep don't drink coffee or tea or have a cigarette just before going to bed.

Summary

Anxiety, depression, anger and tiredness are all natural reactions to difficult circumstances.

You can't look after someone else if you are not well yourself

so you have to look after yourself.

Remember to:

Talk to someone

Eat and sleep well

Share the care

Make time for yourself

Relax

Useful Addresses

Headway National Head Injuries Association
7 King Edward Court
King Edward Street
Nottingham
NG1 1EW

Tel. (0115) 9240800

Edinburgh Headway Group
Headway House
Astley Ainslie Hospital
Cannan Lane
Edinburgh

Tel. 0131 537 9116